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ABSTRACT

This report presents results of a self-study evaluation of the Pediatric and Developmental Services (PEDS) unit, a center-based collaborative interagency program in Guam which provides screening, assessment, referrals, and initial intervention for children birth to 3 years of age with or at risk for developmental delays/disabilities and their families. The study utilized the self study instrument developed by the U.S. Department of Education, Office of Special Education Programs, for programs under Part H of the Individuals with Disabilities Education Act. After an introduction, individual sections of the report cover: (1) a review of the Part H Self-Study Instrument; (2) development of the PEDS unit; (3) the current status of the PEDS unit; (4) service delivery of the PEDS unit; and (5) recommendations. Recommendations address the PEDS unit-services expansion, the PEDS unit-research directives and initiatives, and the PEDS unit-evaluation and self-study directions and initiatives. Among 13 appendices, which comprise most of the document, are various memoranda of agreement between Guam and federal agencies, samples of forms used by PEDS, the PEDS policy and procedures manual (1990-91), a sample case, the PEDS brochure, and a research article by J. W. Holstrum entitled "Where America's Special Babies Begin." (DB)

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ED 419 327

# The Self Study Evaluation of the Guam Pediatric Evaluation and Developmental Services (PEDS) Unit

# FINAL TECHNICAL REPORT

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Self Study Team Manager
Contracted Under Guam University Affiliated Programs
May 8, 1997
[Updated Sept. 8, 1997]

EC 306413

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May 8, 1997
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# The Self Study Evaluation of the Guam Pediatric Evaluation and Developmental Services (PEDS) Unit

May 8, 1997
[Updated: Sept. 8, 1997]

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## Authorization

The evaluation of the PEDS unit was recommended by the Guam Interagency Coordinating Council (GICC) and authorized by the Guam Department of Education (Guam DOE), the designated Lead Agency for Part H Programs for Guam. This report was funded under the Part H subcontract to the Guam University Affiliated Program (Guam UAP) as an activity in the Early Intervention Initiative Area. The Guam UAP is a federally funded program administered under the University of Guam (UOG), located on the UOG campus, Dean's Circle, House #11. The original report was delivered on May 8, 1997 then, updated on September 8, 1997. Any comments, concerns, or questions regarding this publication may be directed to Velma A. Sablan, Ph.D., College of Education UOG Station, Mangilao, Guam 96923.

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# I. Introduction:
# Purpose and Goals of the PEDS Evaluation

## Introduction

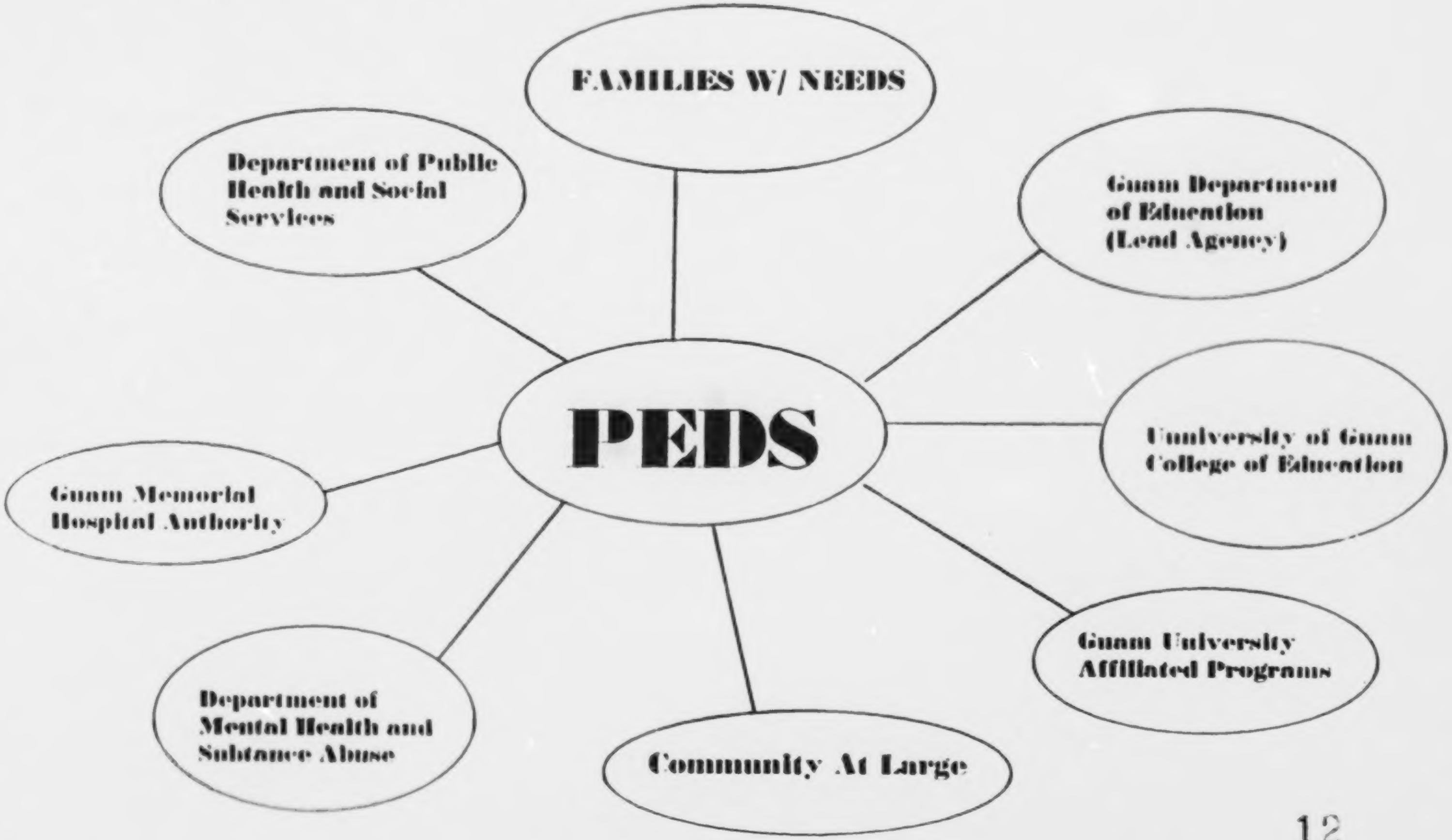
The Pediatric and Developmental Services unit (PEDS) is a center-based, collaborative interagency program in Guam which provides screening, assessment, referrals and initial information/intervention for children birth to 3 years of age with or at risk for developmental delays/disabilities and their families. PEDS is located on the University of Guam (UOG) campus, Dean's Circle, House #17 in Mangilao. It is under the administration of the Guam Department of Education (Guam DOE), the lead agency for Part H programs and UOG. The Guam Interagency Coordinating Council (GICC) serves as the advisory council to PEDS as stipulated by PL 99-457. The Guam University Affiliated Program (GUAP) is currently subcontracted by the lead agency, to provide technical support to PEDS and is identified under the Early Intervention Initiative Area. The Department of Public Health and Social Services (DPH&SS), Guam Memorial Hospital Authority Authority, (GMHAA), and the Department of Mental Health an Substance Abuse (DMH&SA) are other stakeholding agencies who are involved in the PEDS interagency program. Exhibit 1 gives a diagram of the collaborative interagency structure of PEDS.

## A. Purpose of the PEDS Evaluation

The purpose of the PEDS Evaluation is to assist the GICC, Guam DOE, GUAP, UOG, GMHA, DPH&SS, DMH&SA, families, and other service agencies and individuals, concerned with supporting improved outcomes for the birth to three population with disabilities or those at high risk, with necessary information to guide decision making in the operation of PEDS.

## PEDS-A GUAM INTERAGENCY UNIT
Serving Families of Infants and Toddlers

Exhibit 1


FAMILIES W/ NEEDS
Department of Public Health and Social Services
Guam Department of Education (Lead Agency)
PEDS
University of Guam College of Education
Guam Memorial Hospital Authority
Guam University Affiliated Programs
Department of Mental Health and Subtance Abuse
Community At Large

## B. Goals of the PEDS Evaluation

The PEDS evaluation was designed to meet five major goals

| | |
|---|---|
| Goal 1: | Review the Self Study process recommended by OSEP-USDOE and field test the process through the PEDS evaluation to determine usefulness for Part H programs in Guam. |
| Goals 2: | Document the historical development of PEDS. |
| Goal 3: | Determine the current status of the PEDS Unit, including staffing pattern, operating procedures, physical plant, and fiscal resources. |
| Goal 4: | Review PEDS service delivery model and present issues critical to serving infants and toddlers with disabilities and their families in Guam. |
| Goal 5: | Submit recommendations based on all findings for the future of PEDS. |

## C. Evaluation Questions

Evaluation questions were posed which guided the evaluation after meetings with GICC, PEDS, GUAP and others. Questions were organized around the five goals of the evaluation and were as follows:

1. What is PEDS?
2. a. What is the OSEP-USDOE Self Study process?
   b. What is its purpose?
   c. Who is it designed to serve?
   d. What implications does it have for PEDS?
3. a. What is the historical development of PEDS?
   b. How does PEDS integrate into the lead agency's Part H goals?
   c. What is the current authority base for PEDS?
   d. What agencies sanction PEDS?
   e. What Agreements are in effect for PEDS?

f. What are critical elements to these Agreements?

g. What are future directions for these interagency agreements for PEDS?

4. a. What is the status of the PEDS Staffing Pattern?

b. What are areas of need?

c. Has there been adequate utilization of all personnel?

d. What assurances have been put in place for personnel recruitment and ongoing professional competency currently and in future?

e. What are PEDS operating procedures?

f. What are areas of strength and weakness?

g. Are operating procedures clear and understandable?

h. Where can improvements be made?

i. What is the status of the PEDS Physical Plant?

j. What aspects of the physical plant should remain unchanged?

k. Where can improvements be made?

l. What are PEDS fiscal resources?

m. How has PEDS managed these resources?

n. What are projected needs and costs?

5. a. Has PEDS provided the service to the birth to 3 year population that it was designed to serve?

b. What evidence is there to suggest that services to the birth to 3 year population have been provided?

c. What are strengths and weaknesses that have been identified by both families and service providers?

6. Given the findings from above, what are recommendations for improvement to implement needed changes for the PEDS unit?

## D. Data Sources for the PEDS Evaluation

Because of the interagency collaborative support which forms the basis of the PEDS unit, the task of data collection came from multiple sources and participants over a 12 month period including:

1. Meetings with the PEDS staff, group and select individual interviews with each staff member
2. Review of all CDSC/PEDS MOUs and available Annual Reports obtained from the Part H Coordinator
3. Records and files on the PEDS site
4. Meeting minutes from GICC where PEDS activities are referenced
5. Meeting minutes from the PEDS Ad Hoc Committee at their monthly meeting
6. Input from the Part H Coordinator, Guam DOE
7. Input from the Guam UAP Early Intervention Initiative Area Coordinator
8. Input from the Director, Guam UAP
9. Recommendations made by Dr. Allen C. Crocker, M.D., Guam UAP consultant who made a site visit to PEDS in October, 1995
10. Special Education Program Coordinator, College of Education, UOG
11. Interviews with Families who have received or are currently being served by the PEDS unit
12. Site Observations of PEDS service delivery
13. Vital statistics on births from the Department of Public Health
14. Interviews with the former Director of PEDS Unit
15. Interviews with Professionals, i.e. Physicians, Nurses, Other
16. State Directors of 0-3 Programs (State of Hawaii)
17. On-site Observations at GMHA-NICU
18. Review of Publications disseminated by PEDS, i.e. brochures, forms used, degree programs, research articles, etc.
19. Review of current national publications in Early Intervention, i.e. Zero to Three/National Center for Clinical Infant Programs
20. Other data sources identified as process proceeded

In conclusion, the PED Evaluation was designed to assist stakeholders from various agencies, including the Guam DOE, GUAP, UOG, GMHA, DPH&SS, DMH&SA, and the community at large, in decision making and future planning for the birth three population with disabilities/or at developmental risk and their families. It posed 30 evaluation questions and organized these questions around five major goals, with 20 identified data sources, delineated above.

## II. Review of the Part H Self Study Instrument (OSEP-USDOE)

### Introduction

The Office of Special Education Programs, U.S. Department of Education issued a Draft copy of the Part H Self Study Instrument, Version 1.2, dated January, 1994. The Final Version of this instrument was published in October, 1995 and disseminated to Part H Coordinators through the National Early Childhood Technical Assistance System (NEC*TAS) at its 1995 Annual Part H Meeting, November, 1995. This section will describe the OSEP-USDOE Self Study process and instrument, the modifications made for the PEDS Evaluation. It also describes strengths and limitations of this process for Guam.

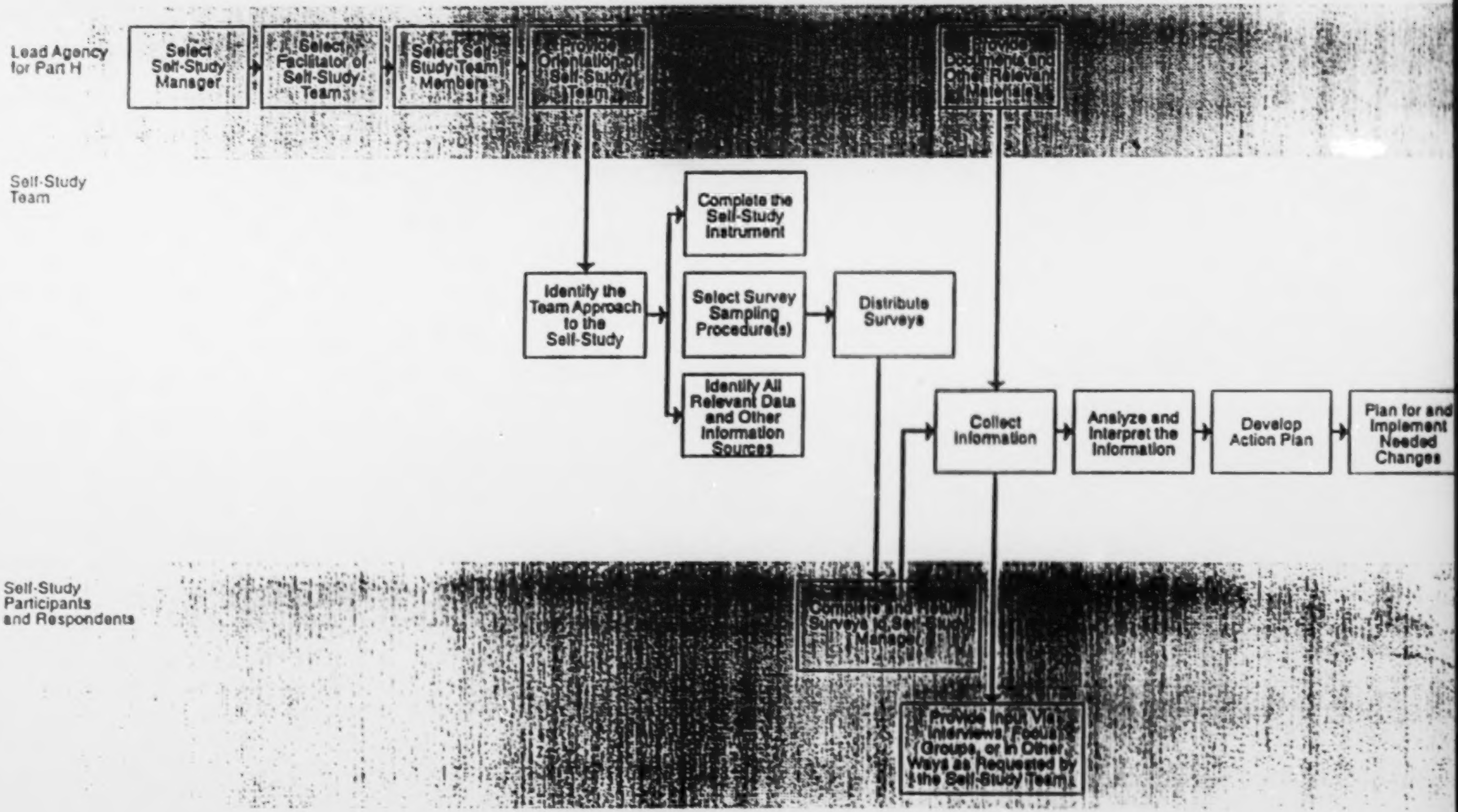
### A. The Study Study Process

The Part H Self Study Instrument was designed to develop a comprehensive, internal evaluation model for a state's early intervention system for infants and toddlers with special needs. It was designed to comprehensively assess critical aspects and components of a state's system in order to better understand the State's capacity to implement each component of the early intervention system. It strives to develop a specific plan of action which can be implemented to enhance the system. The rationale behind the use of a self study process is to develop participant ownership and commitment to Part H mission and goals, resulting in greater motivation to solve problems and improve the State's early intervention system.

> *The self-study process is the first step of a multi-step process for monitoring your State and local Part H delivery system. It can be used to evaluate systematically the early intervention program--either at the State or local level--including its accomplishments, future goals, and needed improvements. The results can then be used to develop specific action plans for making systemic improvements and modifications. (Part H Self-Study Instrument, Final Version, October 1995, pg. I-1)*

## Exhibit 2

## PART H SELF-STUDY PROCESS


Lead Agency for Part H
Self-Study Team
Self-Study Participants and Respondents
Select Self-Study Manager
Select Facilitator of Self-Study Team
Select Self-Study Team Members
Provide Orientation of Self-Study Team
Provide Documents and Other Relevant Materials
Complete the Self-Study Instrument
Identify the Team Approach to the Self-Study
Select Survey Sampling Procedure(s)
Identify All Relevant Data and Other Information Sources
Distribute Surveys
Collect Information
Analyze and Interpret the Information
Develop Action Plan
Plan for and Implement Needed Changes
Complete and Return Surveys to Self-Study Manager
Provide Input Via Interviews, Focus Groups, or in Other Ways as Requested by the Self-Study Team

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The PEDS evaluation is a first level attempt to field test the self-study process and to make recommendations to the lead agency on the viability of self study for Guam. PEDS represents a collaboration of agencies who provide services to infants and toddlers with disabilities. PEDS is a component of the larger interagency Part H delivery system serving Guam. If the PEDS self study evaluation process is found to support decision making then the implication for success in using the Self Study process for Part H becomes meaningful.

The OSEP-USDOE self study process is a three-part system:

Part 1: The use of a self study instrument to be used by self study team to document accomplishments and concerns within a state's early intervention program

Part 2: A program review survey for service providers designed to capture the opinions of service providers about the services offered and provided to infants and toddlers with special needs.

Part 3: A program review survey for family members that gives families within the State an opportunity to capture their comments on the quality of services provided to their child.

The Part H Self Study process requires the selection of a Manager and Team Facilitator, who may be the same person, depending on the needs of the participants. The process also requires the Self Study Manager to select a group of individuals to assist in the completion of the self study instrument. The Part H Self Study Process as recommended by OSEP (see Exhibit 2) provides a 3-level flow chart which culminates in actions plans for needed changes. It utilizes survey forms which provide both open-ended questions and Likert scale items for gathering data from prescribed sampling clusters (family members, service providers, agency staff, service coordinators, advocates, ICC members, program evaluators, diagnosticians, and others) and gives respondents an opportunity to generate action strategies and allocation of resource plans. Surveys are completed in 4 major areas: (1) Capacity building and empowerment of Part H delivery system, (2) Capacity building and empowerment of families, (3) Other topics identified by self study participants [these are open ended survey forms where the State can plug in their own topics], and (4) State early intervention program review surveys. A worksheet is provided called "The Self Study Topics and Corresponding Program Review Survey Items" where self study topics are put on a matrix with survey items from the four major areas. Worksheets allow the self study team to summarize the data collected from all respondents and to obtain a list of needs and resources for planning and coordination.

## B. Implications for the Part H Deliver Systems

The major benefit of the self study process is greater participant awareness to work toward specific improvement plans to empower participants, especially families, and to improve the Part H system supporting infants and toddlers with disabilities. Through the self study evaluation process, participants are more likely to:

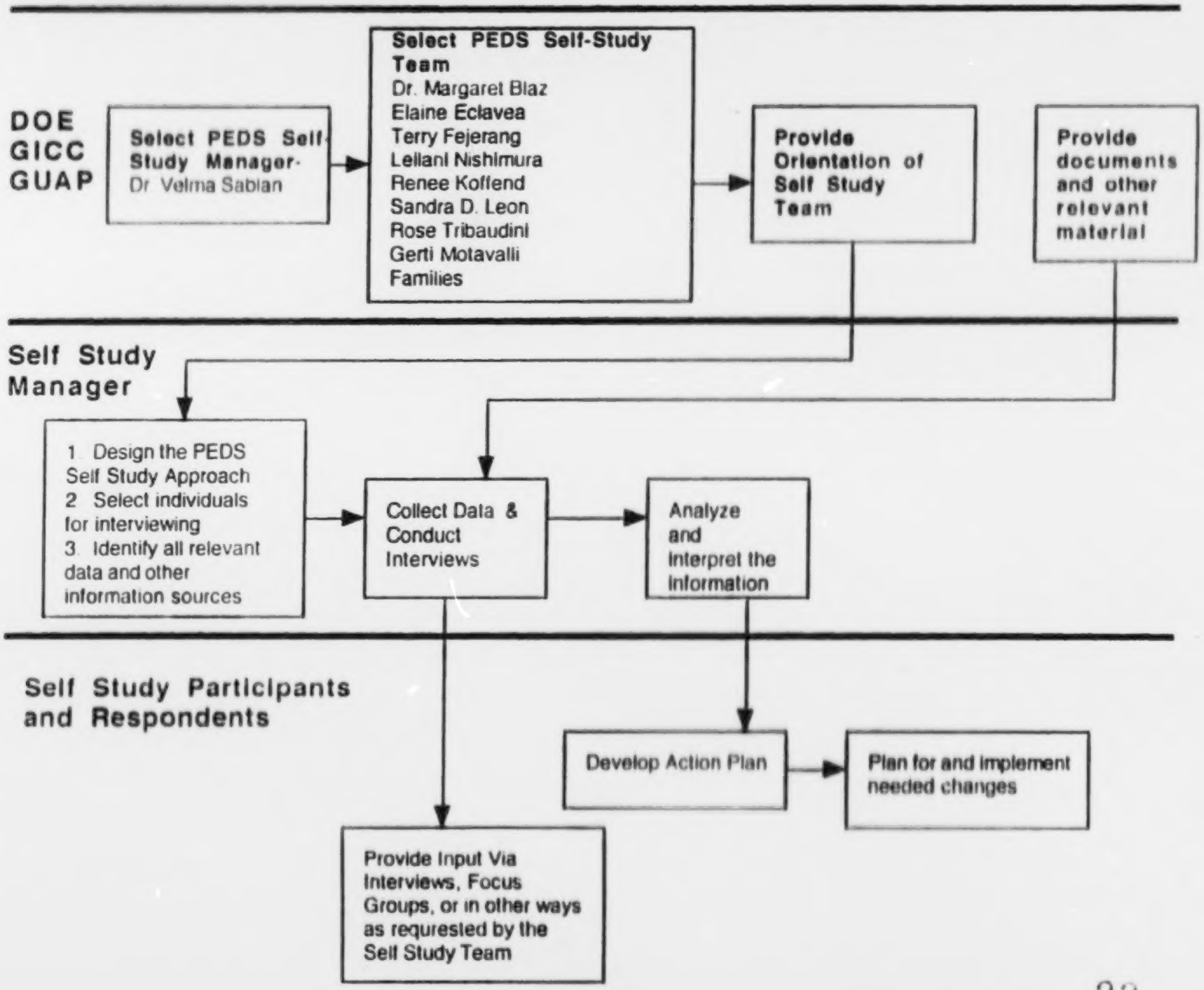
√ comprehensively and realistically assess important program components.
√ provide a more thorough assessment because of familiarity, direct knowledge, and experience with the State early intervention system.
√ take an honest look at the early intervention system and identify areas in need of improvement.
√ become a unified team in evaluating the early intervention system.
√ enter into meaningful dialogue on the early interventions system.
√ strengthen interagency partnerships.
√ foster trust and open communication between the State and OSEP.

## C. Adaptations for the PEDS Evaluation Process

The PEDS Evaluation retained the basic format of the Part H Self Study process and utilized a qualitative data gathering format (rather than surveys), where interviews with a purposive sample and relevant material, were gathered (see Exhibit 3).

Exhibit 3

## PEDS Evaluation: An Adaptation of the Part H Self Study Process


DOE
GICC
GUAP
Select PEDS Self-Study Manager- Dr Velma Sablan
Select PEDS Self-Study Team
Dr. Margaret Blaz
Elaine Eclavea
Terry Fejerang
Leilani Nishimura
Renee Koffend
Sandra D. Leon
Rose Tribaudini
Gerti Motavalli
Families
Provide Orientation of Self Study Team
Provide documents and other relevant material
Self Study Manager
1. Design the PEDS Self Study Approach
2. Select individuals for interviewing
3. Identify all relevant data and other information sources
Collect Data & Conduct Interviews
Analyze and Interpret the Information
Self Study Participants and Respondents
Develop Action Plan
Plan for and implement needed changes
Provide Input Via Interviews, Focus Groups, or in other ways as requrested by the Self Study Team

The PEDS Evaluation was intended to be an internal assessment of the PEDS operation and could only approximate the process that would normally be used for a State's Part H evaluation process. The survey process must be carefully evaluated with Pacific island populations, as most culture groups are less inclined to provide written feedback on survey forms and are more prone to give richer information and details when face to face conversational interviews are conducted. While survey forms help reach a wider number of respondents and saves time in data collection, the probability of obtaining misleading or incomplete information from Pacific island respondents is significant which must be carefully considered in adopting the Part H Self Study process.

The implication of the PEDS evaluation for families of infants and toddlers are significant. Through this self study process, families will have a voice in which to describe their experiences in obtaining services for their infants and toddlers, in order to make recommendations to improve the quality of services provide by PEDS. Families will be afforded the opportunity to document areas of strength and weakness in the PEDS system of service delivery, pointing out aspects of the current PEDS operation which should be maintained.

The Part H Self Study Process contains 8 steps in which questions are posed within 15 target topic areas. The PEDS Evaluation will follow this 8 step process for completing its self study. The 8 process steps are:

Step 1. Select a Team Manger and Team Facilitator for the Self Study
Step 2. Select Self-Study Team Members
Step 3. Introduce the Self Study Concept to Participants
Step 4. Identify the Team Approach
Step 5. Collect Information
Step 6. Analyze and Interpret the Information
Step 7. Plan for Improvement and Implement Needed Changes
Step 8. Describe the Process Used in Conducting the Self Study

# III. Development of the PEDS Unit

## Introduction

This section reviews the historical treatment of infants and toddlers with disabilities in Guam, followed by a description of programs funded under various legislation, beginning with the 1965 PL 89-313 ammendment to the Elementary and Secondary Education Act to EHA-Part H-PL 99-457 and the subsequent 1991 IDEA PL 102-119. From this historical context, the major points of Memorandum of Agreements are reviewed which established PEDS (formerly known as the Children's Developmental Services Center (CDSC) from 1988 to the present.

## A. Brief Overview: Historical Treatment of Infants and Toddlers with Disabilities in Guam

In many Pacific island cultures, including the Chamorro people of Guam, a child with a visible disability, such as cleft palate, Down's Syndrome, or other visible physical abnormality was viewed from two perspectives by the predominately Christian population. One view was, the child was a "curse" or a "punishment" from God because of some sin committed by the mother or father, a member of her clan, or a sin committed by somebody in the family who lived generation(s) earlier. The other view was, the child was a gift from God and it was the mission of the family to do whatever necessary to spare the child from social ridicule, especially when the child was born in wedlock. These beliefs still exist but, are slowly changing as information on prenatal, perinatal, and postnatal anomalies and abnormality are more widely understood. In keeping with these early beliefs, parents prior to and just after World War II, often kept the infant or toddler with a disability at home out of sight, hidden from public view, to limit public exposure of an infant with a disability, particularly when the child was born out of wedlock. Unmarried mothers of these infants, knowing little about the care of normal infants, let alone knowledge of the infant with special needs, would frequently keep their babies in cribs all day, making contact only when necessary for feeding and changing. Bonding between the infant with a disability and an unmarried mother seldom occurred, as unmarried mothers had to deal with the admonishment of their families for bringing shame to the clan. Chamorros however, have no history of infanticide in their culture. Infants grew to adulthood and would be provided custodial care by their families throughout their lives. Infants with more fragile conditions did not often survive due to the limited health care available in Guam prior to World War II.

After World War II and the entry of U.S. Navy physicians and nurses, health care improved. Programs were initiated to provide health care to all infants through well baby clinics and immunization programs offered through the military hospital and later Public Health. By the late 1950s and early 1960s, Public Health nurses were located in every village (often in quonset huts or in the public school building) to provide nursing services to village families. The treatment of minor injuries, lice, prenatal care, nutrition information, well baby checkups, and basic nursing services were provided by the village Public Health nurse. Mothers who brought in an infant with a disability were often counseled on how to manage care and feedings, outside of these services, mothers were often left on their own to figure out how to intervene for their infants on everything else.

With the construction of the Guam Memorial Hospital Authority, Public Health nurses became center-based when the Department of Public Health was housed in the GMHA wing. Public Health Nurses would go out to villages and assist families which meant referrals and consultations could happen more efficiently. Although ESEA PL 89-313 became law in 1965, children with disabilities who were under the age of 5 years were typically kept at home. School-aged children with disabilities were often placed in segregated "special education" classrooms within the schools and were excluded from the regular classroom. Meanwhile, under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, the Social Security Act amendments, PL 90-248, hearing screening, nutritional, dental, and other services under Maternal Child Health-Crippled Children's Services were offered to eligible children. The ruebella epidemic of the early 1960s in Guam left many children with mild to severe hearing losses, a significant number of cases were found among preschoolers and school-aged children. Although Head Start programs were established under Project Head Start in 1968, preschoolers with disabilities were often excluded, as Head Start teachers were untrained in the mangement of preschoolers with special needs. By 1972 however, with the court decisions of *Mills v. board of Education (1972)* and *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania (1971,1972)*) in the United States mainland, Head Start were required to ensure that at least 10% of the children served were children with disabilities. This expanded opportunties for preschool children with disabilities.

Under the 1968 PL 90-538, the Handicapped Children's Early Education Program (HCEEP) and the 1970 ESEA amendment PL 91-230, preschool programs were established in the public schools, with services to preschoolers primarily being offered at Brodie Memorial School, a day school for children with moderate to severe disabilities. The Department of Public Health & Social Services established two model programs: (1) the preschool deaf program and (2) the preschool program for language disabilities. These model programs were designed primarily to assist parents in learning how to work with their toddlers and preschoolers in the home. The youngest child in the program was 2 years old and the oldest was 5 years old, both were children with severe hearing losses. Like many programs funded, these early programs demonstrated that early intervention made differences for young children with disabilities. More important, it modeled for many skeptical Chamorro families, that structured learning programs for toddlers and preschoolers were viable and produced results.

By 1973 the Rehabilitation Act's section 504 began to impact Guam's awareness of the mandate to remove barriers that excluded individuals with disabilities as many agencies complied with accessibility issues. By the time U.S. Congress enacted the 1975 Education for All Handicapped Children Act (EAHCA) PL 94-142, Guam had already been serving toddlers and preschoolers with disabilities in the public schools. This landmark legislation provided the needed funding to expand services for this age group. In 1977, the Department of Public Health, under the MCH program received funding for the Home Training Project, a program designed to support infants and preschoolers with disabilities in the home. The program operated for 3 years then transferred to the Guam DOE where children in the birth to 24 month age group were not extensively served primarily due of Guam's lack of trained specialists in early intervention. In 1982, the University of Guam, College of Education with the support of the Guam DOE Divsion of Special Education, hired an adjunct professor in Special Education with a specialty in early intervention to develop training programs in early intervention and later, to develop programs for the birth to three year age group with disabilities.

By 1986, with the signing of PL 99-457 funding for birth to three programs became available and states applied for available funding to support the planning and implementation of early intervention programs. Like the experiences of the mainland U.S., initial problems were experienced. Territoriality over which services were the purview of which agencies caused intense conflicts. Interagency agreements were entered into with great caution and apprehension. Bowe (1995) stated:

> However, for a variety of reasons, most notably financial constraints and problems establishing the necessary interagency agreements, many states told the U.S. Department of Education that they would miss the Part H deadline. The 1991 IDEA amendment, PL 102-119 gave states up to two additional years to comply with Part H.

By 1991 however, Guam had already entered into three major interagency agreements which provided services to the birth to three year age group with disabilities. The first of these agreements established the PEDS unit, which was originally known as the Children's Developmental Services Center (CDSC). These MOAs specified annual reporting requirements, specifically budget needs, expenditures, number of children served, and training, observation, or practicum experiences provided. A brief review of the highlights of the MOAs, will demonstate how Guam accomplished the interagency requirement specified in PL 99-457 in serving the birth to three year olds with disabilities or who are at risk.

## B. Establishment of the PEDS Unit

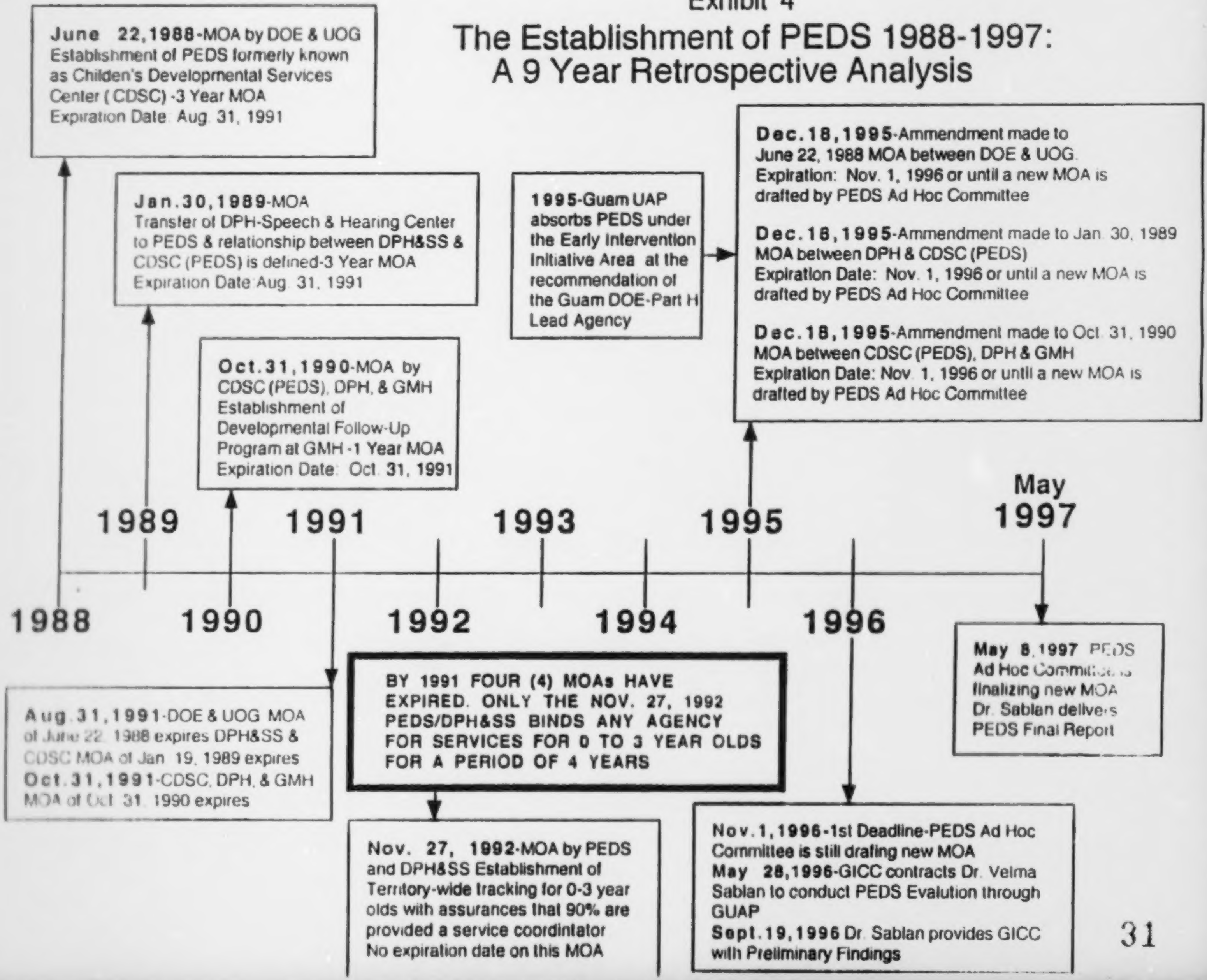
As Guam responded to the need for the development of interagency agreements among programs which provided service to the birth to three population, the need for a transdisciplinary approach to assessment and training was necessary. A transdisciplinary model is a team approach where parents are full and active members of the assessment team. The guiding philosophy of the transdisciplinary approach is, "team members make a commitment to teach, learn, and work together across discipline boundaries to implement unified service plan(s)." (Cohen & Spenciner, 1994, pg. 29).

With the need to train individuals in early intervention in Guam and the establishment of a graduate training program in early intervention, Guam DOE entered into an agreement with the Univerity of Guam to develop a program on the UOG campus which would bring together professionals in a transdisciplinary approach to provide services for the birth to three year age group with disabilities, while simultaneously developing a training and research site for graduate students in early intervention. When the first MOA was signed between Guam DOE and UOG, Dr. Heidi Farra San Nicolas assumed the acting Director role for PEDS while recuitment for a permanent Director was taking place. During this transition period, the PEDS center itself was being refurbished and furnished. Dr. San Nicolas's UG-1 documenting her role as acting Director for PEDS is provided in Appendix A.

Exhibit 4 summarizes the Memorandums of Agreement (MOAs) which established PEDS on June 22, 1988 up to the most recent Ammendment to the MOAs, signed on December 18, 1995 and includes the current effort to finalize a comprehensive interagency MOA by the PEDS Ad Hoc Committee. Over the nine (9) year period of PEDS existence, three (3) MOAs were entered into, which governed PEDS. The first Interagency Agreement was signed between Guam DOE and UOG on June 22, 1988, for a three year period. The second MOA was entered into between DPH&SS and CDSC (PEDS), also for a three year period. The third MOA was between CDSC and GMHA, signed on Oct. 31, 1990 for a one year period. All MOAs carried a statement

Exhibit 4

# The Establishment of PEDS 1988-1997: A 9 Year Retrospective Analysis



**June 22,1988**-MOA by DOE & UOG
Establishment of PEDS formerly known
as Childen's Developmental Services
Center ( CDSC) -3 Year MOA
Expiration Date: Aug. 31, 1991

**Jan.30,1989**-MOA
Transfer of DPH-Speech & Hearing Center
to PEDS & relationship between DPH&SS &
CDSC (PEDS) is defined-3 Year MOA
Expiration Date:Aug. 31, 1991

**Oct.31,1990**-MOA by
CDSC (PEDS), DPH, & GMH
Establishment of
Developmental Follow-Up
Program at GMH -1 Year MOA
Expiration Date: Oct. 31, 1991

**Aug.31,1991**-DOE & UOG MOA
of June 22, 1988 expires DPH&SS &
CDSC MOA of Jan. 19, 1989 expires
**Oct.31,1991**-CDSC, DPH, & GMH
MOA of Oct. 31, 1990 expires

**BY 1991 FOUR (4) MOAs HAVE EXPIRED. ONLY THE NOV. 27, 1992 PEDS/DPH&SS BINDS ANY AGENCY FOR SERVICES FOR 0 TO 3 YEAR OLDS FOR A PERIOD OF 4 YEARS**

**Nov. 27, 1992**-MOA by PEDS
and DPH&SS Establishment of
Territory-wide tracking for 0-3 year
olds with assurances that 90% are
provided a service coordintator
No expiration date on this MOA

**1995**-Guam UAP
absorbs PEDS under
the Early Intervention
Initiative Area at the
recommendation of
the Guam DOE-Part H
Lead Agency

**Dec.18,1995**-Ammendment made to
June 22, 1988 MOA between DOE & UOG.
Expiration: Nov. 1, 1996 or until a new MOA is
drafted by PEDS Ad Hoc Committee

**Dec.18,1995**-Ammendment made to Jan. 30, 1989
MOA between DPH & CDSC (PEDS)
Expiration Date: Nov. 1, 1996 or until a new MOA is
drafted by PEDS Ad Hoc Committee

**Dec.18,1995**-Ammendment made to Oct. 31, 1990
MOA between CDSC (PEDS), DPH & GMH
Expiration Date: Nov. 1, 1996 or until a new MOA is
drafted by PEDS Ad Hoc Committee

**Nov.1,1996**-1st Deadline-PEDS Ad Hoc
Committee is still drafing new MOA
**May 28,1996**-GICC contracts Dr. Velma
Sablan to conduct PEDS Evalution through
GUAP
**Sept.19,1996** Dr. Sablan provides GICC
with Preliminary Findings

**May 8,1997** PEDS
Ad Hoc Committee is
finalizing new MOA
Dr. Sablan delivers
PEDS Final Report

which allowed for renewal of these MOAs, depending upon the progress made during the first three years.

Between 1992 to December 18, 1995, a period of 4 years, no MOA were renewed, due to administrative oversight and the lack of a Director when Dr. June Holstrum resigned from the position after serving as PEDS Director from 1989 to 1992. Administrative leadership was given to an acting Director, Dr. Margaret G. Blaz, who was detailed through DPH&SS with no additional compensation and was also the Speech Pathologist for PEDS. The PEDS unit continued to function with severe restrictions placed on its administrative needs. Technical issues were faced since the PEDS Director was specified in the Guam DOE &-UOG MOA as a jointly funded position (.50 FTE-UOG & .50 FTE DOE) and recruitment for a new Director was delayed by budget issues, clarification of the role the Part H Coordinator played in PEDS operations, and lack of clarity by the collaborating agencies on the continuation of the PEDS unit. By the Fall, 1995, the Guam UAP absorbed PEDS under the new Early Intervention Initiative Area. On December 18, 1995, with the support of the Guam UAP, Ammendments to all three (3) MOAs were signed which reauthorized the terms of the original MOAs between: (1) Guam DOE and UOG, (2) PEDS and DPH&SS, and (3) PEDS, DPH&SS and GMHA, from December 18, 1995 to August 31, 1996, or *"...until such time that the PED Ad-hoc Advisory Committee drafts a new MOA and has such MOA approved by the respective agencies..."*

A closer inspection of the MOAs which established PEDS, under the leadership of Dr. June Holstrum follows. It will show noteworthy aspects to each of the MOAs which currently sanction PEDS.

### 1. Interagency Agreement of 1988-Guam DOE and UOG-Giving Birth to PEDS

The first Memorandum of Agreement was signed by officials from UOG and Guam DOE on June 22, 1988. Key elements and findings from this MOA are presented in this section. A copy of this MOA is contained in Appendix B.

The key elements and important aspects of the agreement between Guam DOE and UOG are:

- it established an interagency unit for the birth to three population. It was originally called the Children's Developmental Services Center (CDSC), later renamed in 1990 as the Pediatric Evaluation and Developmental Services (PEDS). No existing MOAs use the referent PEDS. The first occurrance of PEDS in any legal document is contained in the Ammendment of Dec. 18, 1996.

- placed the PEDS unit on the UOG campus, as well as the program for 3 to 5 year olds (Guma Nene) in a nearby location and provided screening, assessment, training, and transitioning for this age group.

- mutually administered a program which provided identification/referral, screening, assessment for elibility, monitoring, case management, facilitation of placement, facilitation of transition, and facilitation of intervention services, as well as training and research.

- specified that the Territorial (Guam) Interagency Coordinating Council would be the Advisory Council to PEDS, which was to assist in future development of appropriate services to young children and their families.

- specified the responsibilities of the PEDS Director and clearly indicated that an annual report be submitted for each fiscal year. These annual reports were to specify: (1) budget allocations made for the year, (2) number of children served, (3) budget needs for the following fiscal year, (4) number of students trained or in internships/practicums/special projects. These reports were to be submitted to the Dean, COE and the DOE Associate Superintendent of Special Education.

- required that PEDS maintain a High Risk Registry and monitoring system.

- required that PEDS coordinate a 5 year plan for PEDS which were congruent

Exhibit 5

## SUMMARY OF FINDINGS FROM DOCUMENTS ON PEDS REQUIRED BY THE TERMS OF THE MOAs 1988-PRESENT

(Based on reports made available for review, interviews, & observations)

### 1. Annual Reports

| | Budget | #Children Served | Requested Budget-Next FY | # Student Practicums Internships, SpProjects |
|---|---|---|---|---|
| June 22, 1988-Sept 30,1989 | *NO ANNUAL* | *REPORT* | *INTERAGENCY* | *TRANSITIONING PERIOD* |
| Oct. 1, 1989-Sept. 30, 1990 | $16,600.01 | Not reported | Unclear | Not reported |
| Oct. 1,1990-Sept 30, 1991[1] | $50,000.00 | 672 | $146,000.00 | 57 |
| Oct. 1,1991-Sept. 30, 1992 | -0-[2] | 686 | $146,000.00 (carry over) | 76 + |
| Oct. 1, 1992-Sept. 30, 1993[3] | Not reported | 426 | No request made | Not reported |
| Oct. 1, 1993-Sept. 30, 1994[4] | Not reported | 924 | No request made | Not reported |
| Oct. 1, 1994-Sept. 30, 1995[5] | Not reported | 672 | No request made | Not reported |
| Oct. 1, 1995-Sept. 30, 1996[6] | Not reported | 1046 | No request made | Not reported |
| Oct. 1, 1996-Sept. 30, 1997[7] | Not reported | 1926 | No request made | Not reported |
| Oct. 1, 1997-Sept. 30, 1998 | *PENDING* | *PENDING* | *PENDING* | *PENDING* |

2. **Inventory** -materials, equipment, and supplies under the management of PEDS-Available upon request

3. **Five Year Plans**: 1988-1996-Not available or never submitted
1997-2002-Currently being developed with PEDS Ad Hoc Committee in conjunction with the development of the 1997 MOA

4. **Infant High-Risk Registry:** Original system was developed by UOG Computer Center and was called *Informix Data System*. The system was initiated in the Fall, 1990 term and crashed in the Spring, 1995-all data lost.

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[1] PEDS 2nd year of operation -W. June Holstrum

[2] "As of June 30, 1992, no funds were transferred from DOE to UOG for the operation of the PEDS program. This was very damaging to the progress of the PEDS program and to it's reputation." (Annual Report, 1991-1992, pg. 5)-W. June Holstrum

[3] Annual Report Dated: October 18, 1993 by Margaret Blaz

[4] Annual Report Dated October 7, 1984 by Margaret Blaz

[5] Annual Report Dated: December 7, 1994 by Margaret Blaz

[6] Annual Report Dated: December 12, 1995 by Margaret Blaz

[7] Annual Report Dated: December 11, 1996 by Margaret Blaz

with the goals and objectives of the Guam Early Childhood Special Education State Grant. A summary of findings of annual reports for the eight (8) year period is presented in Exhibit 4.

**Findings:** Beginning October 1, 1989 to September 30, 1996, an eight (8) year period, only four (4) reports could be obtained. The 1990-1991 & 1991-1992 Annual Report were the only reports done in line with the MOA's specifications.

### 2. Interagency Agreement of 1989-DPH&SS and CDSC (PEDS)-Transferring the Speech and Hearing Center

The second Memorandum of Agreement was signed by officials from DPH&SS and CDSC (PEDS) on January 30, 1989. Key elements and findings from this MOA are:

- CDSC (PEDS) entered into the MOA as an interagency entity representing the interests of Guam DOE, the lead agency, and UOG.

- DPH&SS transfered personnel, equipment, and material to CDSC

- DPH&SS made this transfer with monitoring procedures delineated. CDSC was to keep an inventory of equipment and supplies. The Speech and Language Pathologist, Supervisor, Dr. Margaret Blaz was to submit an Annual Performance and Work Plan Report to the Administrator of Bureau of Family Health Services. The report was to include the number of diagnostic services Dr. Blaz provided, supported by a statistical report. As Acting Director of PEDS, Dr. Blaz submitted this report as her PEDS Annual Report to both Guam DOE and DPH&SS. The format for Dr. Blaz's report to DPH&SS did not have all the requirements specified in the original MOA.

- The Agreement continues to be in effect as the 1988 MOA expired on Aug. 31, 1991 and the Dec. 18, 1996 Ammendement renewed the same terms under the 1988 Agreement, until the PEDS Ad Hoc Committee drafted the new MOA.

**Findings:**

The CDSC-DPH&SS MOA was a major demonstration of goals Part H attempted to accomplish: interagency agreements which strengthened services for the Birth to three population to support families. With the transfer of equipment, supplies, and personnel, inventory and human resource for PEDS was strengthened. A copy of the original MOA can be found in Appendix C.

### 3. Interagency Agreement of 1990-GMHA and CDSC (PEDS)-Establishment of the Developmental Follow-Up Program

The third Memorandum of Agreement was signed by officials from DPH&SS and CDSC (PEDS), and GMHA on October 31, 1990. Key elements and findings from this MOA are:

- it granted CDSC staff access to clinical facilities at the hospital to monitor newborns and made developmental screening a routine treatment protocol for at risk infants.

- it allowed CDSC staff the opportunity to make developmental rounds in the special care nurseries and pediatric ward.

- it allowed CDSC to make contact with the parents prior to discharge for continued follow up for at risk infants.

- it specified that CDSC staff would have space in the nursery area for storage of program material.

- it delineated the CDSC as the responsible unit for the planning and execution of the Developmental Follow Up Program for infants with disabilities and those at risk. It required CDSC to provide copies of screening and evaluations for hopsital charts.

- it allowed opportunties for research within the GMHA, including data collection and annual reports of all information contained in the Developmental Follow Up program

- it specified the need for the maintenance of postive relationships between GMHA and CDSC for mutual exchange of information for mutual concerns, problem solving, and reporting.

**Findings:**

A major cornerstone was laid with the signing of this MOA. This was the formalization of a relationship between medical and educational professionals for early contact with families. It laid the foundation for mutual collaboration and integrated developmental screening for disabling conditions as part of the newborn protocol to assist in early identification and monitoring. This MOA closed the gap for seamless services for infants as agreements were now in place within the local Public Health agency and hospital for early identification and intervention. Public awareness efforts for physicians in private practice, clinics, and the community at large were ongoing. A copy of this MOA can be found in Appendix D.

### 4. Interagency Agreement of 1992-DPH&SS and PEDS-Establishment of Territory Wide Tracking for 0-3 Year Olds

The fourth Memorandum of Agreement was signed by officials from DPH&SS and CDSC (PEDS) on November 25, 1992. Key elements and findings from this MOA are:

- it recognized the need for a mutal systems management effort to track and monitor the needs of 0-3 year old children with special health needs and their families.

- it recognized that services are often fragmented or had gaps in some service delivery areas serving the needs of 0-3 year old children with special health needs and their families.

•it specified that the Department of Public Health and Social Services, Bureau of Family Health and Nursing Services, Maternal and Child Health Program, would assume the responsibility of systems management for children with special health needs, called The Children with Special Health Needs System Management Project.

•it specified that a territory-wide information management system which would include a Central Registry and related tracking activities would be developed by the Department of Public Health and Social Services, Bureau of Family Health and Nursing Services, Maternal and Child Health Program

•it stated that the coordinated interagency information management system would meet the identified data needs of all agencies who provided services to to 0-3 year olds children with special health needs.

•it developed methods for eliminating gaps in service delivery, set the context for extended agency collaboration of services and insured that 90% of all 0-3 year olds with special health needs would be provided with a designated care partner/service coordinator

•it specified that PEDS would be responsible for completing and submitting data to the the CSHN Systems Management Project, including data gathered from GMH.

•it provided for parent consent for to enroll the child in the CSHN Central Registry and management when parental consent could not be obtained.

**Findings:**

This MOA formally acknowledged the DPH&SS as the agency responsible for the comprehensive tracking and monitoring of services to all 0-3 year olds with special health needs. It provided detailed descriptions of the relationship that the PEDS unit would have in collaborating with DPH&SS in the tracking process. It provides further evidence of Guam's agencies in developing a system which would prevent duplication of services and other systemic redundancies in service delivery. A copy of this MOA can be found in Appendix E.

### 5. PEDS Administrative Dormant Period-

Under the administrative leadership of Dr. June Holstrum, the administrative needs of the PEDS unit was significantly extended, however the cross utilization of Dr. Margaret Blaz as both acting Director and the only full time Speech and Language Pathologist providing service to PEDS had an impact on administrative directions. PEDS continued to operate, providing screening, diagnostic and referral services to families, as well as determining eligibility, assisting in the development of Individualized Family Services Programs (IFSPs), and in transitioning Part B program. However, the lack of a full time Director, continued budget management issues, difficulties in obtaining needed supplies, technical equipment, and clerical support created significant challenges for the PEDS staff.

This period is best characterized as PEDS administrative dormant phase. The in-house database for PEDS was obsolete and efforts to upgrade the system did not occur as The Children with Special Health Needs System Management Project under DPH&SS was being developed, however it too encountered delays. Two of PEDS staff members vacated their positions and the turnover created backlogs. The assessments of the three to five year old group was transferred to Guam DOE Special Education Services. Yet, despite these obstacles, in 1993-94, PEDS reported serving 924 children, the highest number of children served since the creation of the unit, based on available annual reports. It also continued its commitment to continue supporting families, training its staff members, developing public awareness, and advocating for infants and toddlers with special needs. The Part H Coordinator assisted PEDS with administrative issues, but the need for a full time Director became critical. By early 1995, the Guam University Affiliated Program (GUAP) was funded and technical support was provided to assist with PEDS administration and monitoring. The GUAP initiated the renewal of PEDS interagency MOAs through an ammendment (see Appendix F) to the agreements and established the PEDS Ad Hoc Committee to assist in the development of a new interagency MOA and to coordinate a 5 year plan

### 5. Future Directions of PEDS Interagency Agreements

At this writing, the PEDS Ad Hoc Advisory Committee is in the final stages of completing the new interagency MOAs for PEDS. A key feature of the new MOA is that all the agencies involved with providing services to the birth to three population are included in the agreement. Responsibilities that PEDS will have in its relationship with these agencies is being clearly delineated. While future needs of families in Guam are unpredicatable, the influx of people from surrounding Micronesian islands has created new challanges in terms of meeting the needs of culturally diverse groups. The increase of illegal drug use among child-bearing women is yet another factor which will affect infant outcomes and emphasize the need for early intervention. The continued rise in the number of teen pregnancies in Guam will continue to require intervention for at risk children. These are but three factors among many, which will create the need for expanded services for young children. Faced with a lack of trained human resources, declining budgets, and the increasing needs of changing family structures in Guam, collaboration and cooperation among agencies becomes imperative.

This analyses of the MOA governing PEDS led to the following areas which planning should consider:

1. Future MOA should become family-focused/family-centered. In the first 9 years of MOA creation and subsequent operation, agencies were protective of their of property, personnel, funds and other "turf control" issues. Agencies are now postured to negotiate agreements with a sense of trust and openness, the turf wars are over, supporting families in need should become the next level of focused awareness. Agencies should now make family-centered discussions at the core of

their negotiating process. Development of expanded services must take into consideration growing population rates, realistic growth in the expansion of services, and the creative and innovative uses of scarce funding. In Exhibit 6 Guam's birthrate from 1990, 1991, and 1993 show a consistent 10% increase When these statistics are paired with PEDS # of children served, it appears that PEDS tends to serve anywhere from 17 - 21%

Exhibit 6

Population Growth Trends-Rate of Live Births and PEDS Statistics

| | 1990 | 1991 | 1993 |
|---|---|---|---|
| Guam Population | 133,152 | 136,773 | 143,403 |
| Number of live births in Guam | 3,850 | 3,921 | 4,409 |
| Percent of Population | 3% | 3% | 3% |
| # Children Served by PEDS | 672 | 686 | 924 |
| Rate of Live Birth by # Children Served-PEDS | **17%** | **17%** | **21%** |

Average rate of Live Birth by # Children Served-PEDS: 17%
Population Growth Rate (averaged over this 3 year period): 10%

**There is a significant margin of error here since PEDS serves children from birth to three years.*

**Based on Statistical Reports, Office of Vital Statistics Guam and PEDS Annual Reports**

of the number of live births in Guam. When planning for service expansion for the next 5 years, agencies should plan for the expansion of services with these rate in mind. Live birth represent 3% of Guam's population. PEDS tends to serve an average of 17% of the live birth population each year.

Getting large numbers of individuals to profit from limited services, without compromising quality should be considered. Parent support group programs, professional development forums, and other activities are directons that are recommended.

2. MOAs should consider including a clear statement on relationships to Early Childhood Programs, as these are designed for larger groups of children within "for profit-making" as well as non-profit child care facilities. Consider what expectations in terms of support the agency will be willing to desire/consider to promote early intervention within early childhood programs.

3. Budget management has seriously affected planning and continuation of services. While Part H funds compose the largest share of support to PEDS, the contribution of other agencies, i.e. DPH&SS, and private and personal donations and contributions also consititute support. MOAs should have clear statements on PEDS budget management and both the Lead Agency and the GICC should closely monitor not only allocation and expenditures, but the timely transfer of funds, private contributions made to PEDS in terms of funds and equipment and other potential areas where PEDS can expand its assets.

4. MOA should clearly delineate the Annual Report format (this should be specified in PEDS Policy and Procedure Manual) and GICC should have the PEDS Director present this report at its December meeting. Budget forecasts should be included in the presentation with appropriate justification.

5. The new MOA should be structured so that the basic format will remain unchanged and Ammendments to the MOA can be made as needs and directions change. The first 9 years have demonstrated annual or 3-year renewals may not always be necessary.

## IV. Current Status of the PEDS Unit

### Introduction

This section reviews the PEDS current staffing pattern the professionals and support staff on site, as well as projected recruitment needs and professional competencies. PEDS current operating procedures, as described in its 1990-91 Policy and Procedures Manual, as well as data gathered from interviews with the PEDS staff and on-site observations are presented. PEDS physical plant is described based on interviews with PEDS staff and on-site observations

### A. Staffing Pattern

#### 1. Professionals On-Site

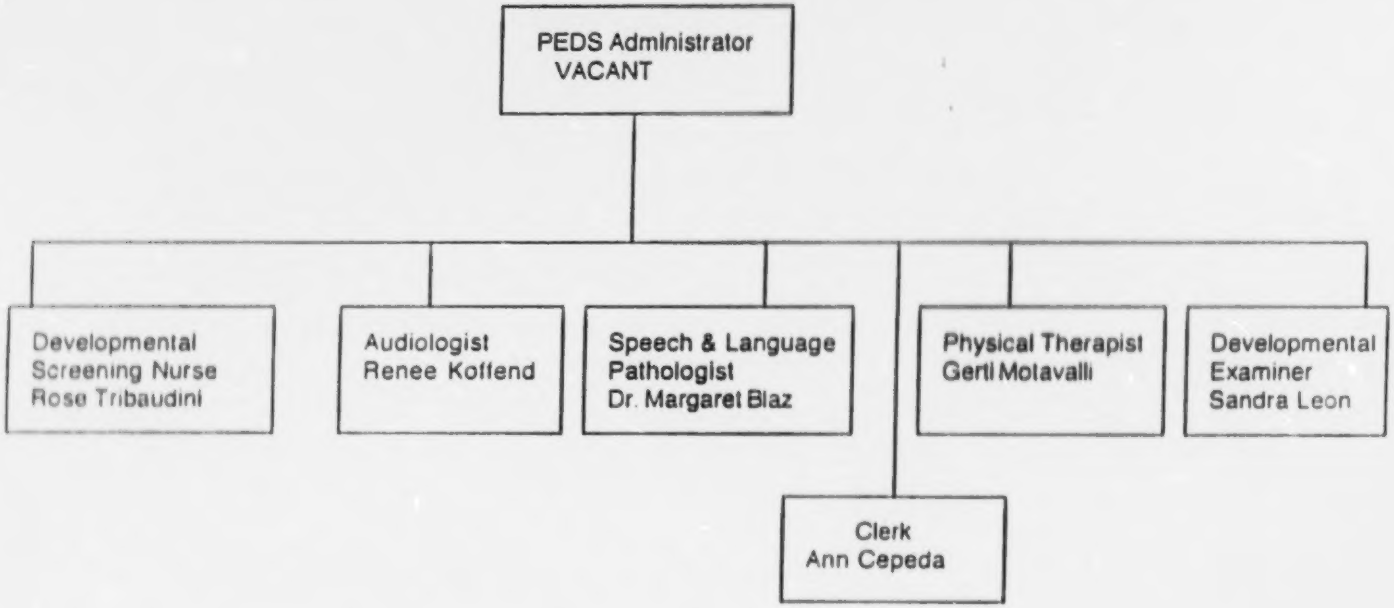
There are seven (7) staff members currently supporting PEDS. An Administrator was hired during the writing of this report as well as a technical assistant/clerk. At the update of this report, the Administrator resigned, seven months after being hired due to another job offer and personal reasons. The list that follows is presented in order of the professional's tenure at PEDS and identifies the agency that provides the position to PEDS.

1. Speech & Language Pathologist - DPH&SS
2. Developmental Examiner-DOE
3. Audiologist -DOE
4. Physical Therapist-DOE
5. Developmental Nurse-DOE
6. Clerk /UOG
7. Administrator, PEDS (vacant)

After the initial findings of this evaluation were presented at the September, 1996 GICC Meeting at the Parc Hotel, a new PEDS Director was hired in March, 1997 prior to the completion of this report. The PEDS in-house Staffing Pattern is presented in Exhibit 7.

## Exhibit 7

## PEDS In-House Staffing Pattern



During the update of this report, discussions have been taking place on **merging the role of the PEDS Administrator and the Part H Coordinator into one position** to provide administrative leadership for all of the Guam Early Intervention effort.

The **need for a Social Worker** to provide services to families and to provide linkage between social service programs and the home was identified as a critical area of need. The Part H Coordinator indicated that Guma Nene/Public Health have Social Workers that could be cross utilized by PEDS, the PEDS staff indicated in an interview on April 12, 1996 that a dedicated PEDS Social Worker is needed to assist with family adjustment, counseling, and other areas. During home visits it was observed that issues such as housing, food stamps, transportation problems and other services which the Developmental Nurse may identify, requires follow through which could impact outcomes for the family.

There is a need for a **second Developmental Examiner** to provide screening and developmental evaluations to the growing population of infants and toddlers who require assessment and further support for training.

There is a **need for Second Developmental Nurse** to bridge the connection between GMHA, PEDS, and the Lead Agency. The current Developmental Nurse is serving the NICU and Nursery where an average of 300 babies are born each month with an average of 60 babies in the NICU or Intermediate Care Nursery each month requiring follow-up care and management. The Developmental Nurse is currently making visits to the GMHA Nursery three times a week and home visits two times a week. While a method has been put in place for her to track most babies, there continues to be the risk of infants falling through the cracks on days when she does not make a visit. Also, the PEDS Developmental Nurse is currently under a teacher contract with DOE which requires that she reapply for her position to provide service to GMHA during the summer months. During the weeks she is reapplying and waiting for paperwork to be processed, no visits are made to the GMHA Nursery or ICU.

The PEDS staff indicated the **need for a consulting M.D.** to get medical input on some children with specific medical issues. The medically fragile infant and those with conditions requiring special management, as well as a physician who can conduct periodic training sessions with the PEDS staff, as necessary, will serve to improve professional competency and services to families.

### 3. Recruitment and Professional Competency

The need to begin recruiting individuals who will assume positions that become vacant as current professionals in early intervention retire or leave Guam is essential, since over PEDS 9 year history, the turnover for a Director, Developmental Examiners, Developmental Nurses, and Audiologists have all taken place. Recruitment in early intervention in Guam is not easily accomplished since the field requires competencies which are integrated into graduate and undergraduate programs in several areas. Bennet & Watson (1993) recommend the following competencies (adapted for Guam) for professionals in early intervention:

1. The ability to observe objectively, child and family behaviors relevant to early intervention programming, being sensitive to the issues of culture, language and diversity.

2. Flexibility to function well in inter-, multi- and transdisciplinary settings and on teams, with the primary target of cooperation and collaboration leading to positive outcomes for 0-5 children and their families.

3. Good listening skills, including the ability to reflect upon experience.

4. Knowledge of and demonstation of skill in problem solving behavior, being fully aware of the need for multiple perspectives that lead to effective outcomes.

5. Negotiation skills

6. Knowledge of, and ability to communicate to multicultural families about, community supports for families

7. Ability to act as consultant (facilitator) for family members, encouraging family members to be advocates and decision makers for their own child.

8. Knowledge and skill in direct service delivery including therapy and other interventions.

Guam has not yet adopted personnel prepartion, licensure, or credentialing requirements for early intervention professionals. The need to establish baseline competencies, at minimum are critically needed.

## B. Operating Procedures

The PEDS staff has managed to maintain operations at a basic functional level through staff cooperation and collaboration. All staff members assist and support one another in intake procedures, sharing equipment, support with scheduling, transportation, and in communicating procedures. There are adopted intake forms, referral procedures, case history forms, and other tracking mechanisms in place that are being regularly used (see Appendix G for samples of forms used at PEDS and Appendix H for a sample of forms used by the Developmental Nurse at GMHA).

A copy of the last Policy and Procedures Manual which was obtained from Dr. June Holstrum, dated 1990-91 is included in Appendix I. This is a 32-page document that gives general information on PEDS, it outlines procedures for first contact of families up to IFSP/IIP development, it provides definitions and criteria for eligibility, plans for establishment of a PEDS database, guidelines for student practicum, procedures for conducting research at PEDS, procedural safeguards, and a sample of forms used at each level. Some policies and procedures contained in this manual are still in place, however, the need for a complete review with updated information is needed. In addition, the revised manual should consider retaining the outline in this manual and enlarging the type to make it easier to read and use. A list of resource contacts and language translators should strongly be considered. The lack of a current Policy and Procedures Manual has been most likely due to the lack of a full time administrative head in the last 4 years.

In the area of PEDS equipment, computer printers are obsolete or are not functioning making report writing difficult to disseminate. Telephone and telephone lines are needed as PEDS has only one line and when in use, it ties up operations. Its location at the reception area,with one extension to a test room, offers no privacy for professionals making sensitive or confidential calls to families. Other needs include (1) access to e-mail and the internet in order to communicate on-line with other professionals, and establish a PEDS website, (2) the need to access information sources which RFK Library may not have available and (3) the need to provide the Developemental Nurse with a portable laptop computer which can be used to for the itinerant work between GMHA, PEDS, and the family residences would alleviate the need for her to carry a large amount of paperwork and will give ready access to data needs when consulting with parents and professionals at remote sites.

The continuity of services for infants once determined eligible by PEDS was expressed as an area of concern. The staff is often unclear if children beyond 3 years of age have been served consistently or if there are areas in which the PEDS staff can offer further support for families. The lack of some feedback process to monitor progress is needed. In addition, more effort to a team approach was indicated by the PEDS staff. Proximity to the Guma Nene staff makes regular contact difficult. The need for longitudinal collaboration among professionals to provide continuity of services for families, requires that contact be scheduled more regularly.

Interdisciplinary training in early intervention with other programs within the University is needed to develop awareness of the PEDS unit and to conduct further research on the birth to 3 year population, coordinate practicum, observation experiences, and to recruit new professionals to the field of early intervention, particularly in nursing, social work, education, and allied health.

Data Management is a serious problem in PEDS. Currently all data gathering is being done by hand using an intake information sheet. The original automated data system that was developed by the UOG Computer Center, called Informix Data System, crashed and a substantial amount of information was lost. The PEDS staff found that the system was very repetitive of demographic information which was tedious and unnecessary, it wasn't user friendly, and lacked a manual for first time users and trouble shooting. It was useful for some data but lacking in other areas. The output lacked a legend for explaining various codes. For audiometric data, the need for more parameters and fields are needed because of the larger age group that is seen by the Audiologist at PEDS. The need for a good data management system as well as maintenance of computer hardware is a critical need. An interview with the Part H Coordinator indicated DPH&SS intends to develop a comprehensive database for health care of birth to 5 year olds. It is anticipated that DPH&SS's database would incorporate the needs of Part H and PEDS, however the progress has been slow in establishing this system, in the meantime, manual data collection and the lack of a system makes any type of report difficult obtain from PEDS.

Eligibility from PEDS-to Infant/Toddler (Guma Nene)-The timeframe from referral to placement is 45 days. Testing backlog creates a bottleneck prior to placement and precious time is lost for this age group. Paperwork bogs down the number of children who can be seen. When a PEDS staff member is ill, cancellations and backlog of both children and reports is staggering. A mechanism for handling absence to alleviate the backlog when cancellations become necessary is needed. The opposite end of this concern is the problem of no shows. The no show rates for evaluations add to the backlog and policies need to be put in place, i.e. an on-call list, to offer available assessment times to other families. Parent enticements and training programs to encourage parents to get more involved with their birth to 3 year children was identified as an area of concern. The need for a translator for different languages within Micronesia is necessary to improve communication and to get better show rates. There is a need for a roster of speakers of Tagalog and the Micronesian languages, as well as other languages.

There is a need for ongoing staff development opportunities to stay up to date on new techniques with the birth to 3 year population. Conference attendance using both on site and telecommunications need to be explored to continue developing skill and competency among early intervention staff. Interagency collaboration with other agencies to attend workshops funded by other agencies, pertinent to serving the birth to 3 year population, is needed to continue developing interagency relationships and in capitalizing on limited training opportunities in Guam.

## C. Physical Plant

The "home like" atmosphere of the Dean's Circle house at UOG has contributed positively and significantly to providing services. Many families, especially Micronesian families, find the present facility warm, welcoming, and comfortable in the home atmosphere of the PEDS unit. Interviews with the PEDS staff clearly indicated a reluctance to the idea of moving PEDS into a school or clincal setting, even though it would mean more floor space. The house that PEDS occupies has been found to be very condusive to a family atmosphere, an aspect which PEDS would like to see retained. At the present time, the PEDS house is approximately 1800 square feet of space and is too small for PEDS growing needs. In addition, PEDS has been in violation of Section 504 as the entryway, bathrooms, observation rooms, and test rooms are not accessible. Furthermore, physical therapy space and specialized equipment is needed. There is no privacy for therapy sessions a growing concern on the issue of sanitation when the floor space used for therapy sessions are also heavily trafficed public areas.

The growing staff compounded by the need for office, equipment and clinical space requires that expansion of the current physical plant be evaluated and a incremental expansion plan for rennovation, funding, and identification of fundings sources-both public and private, be given priority.

## D. Fiscal Resources

Currently PEDS Operating Budget has been between $50,000 to $75,000 over the 9 year period, actual costs must include Guam DOE contributions in personnel, outside of Part H funds that are used to operate PEDS. Salary costs for the PEDS Director compose the large portion of the operating budget and remaining funds are used for equipment, supplies, and consumable material. In addition to audiological and other equipment, PEDS acquired a vehicle for the GMHA contacts and home visits, which was later stolen in March, 1997 and no attempts have been made to replace the vehicle. PEDS requested $146,000 for FY 1990-91, although they did not receive this level of funding from its various resources, $50,000 was transmitted from Guam DOE, Part H to fund its activities. The issue of funding and the need for increased funding for PEDS through Guam DOE, other agencies, or private contributors is an administrative component that has been sorely neglected. The transmittal of funds from Guam DOE to UOG for the operation of PEDS has been, and continues to be a major problem which has impacted negatively on operations and staff morale. The lack of a full-time Director to generate budget needs and projections based on the unit's activities, staff input, and in tracking the use of funds will be resolved with the recruitment of a new Director and the technical support of the Guam UAP.

Funding for PEDS must increase from current levels, if PEDS is going to continue to serve the number of children it has been serving in the past. At the current time, PEDS has been doing an excellent job of keeping operations running despite budgetary limitations and the high quality of service it provides. PEDS has survived turbulent times largely due to resources contributed by other agencies and the commitment and caring of PEDS professional staff, this sentiment was echoed by Dr.

Allan Crocker, M.D. from Children's Hospital in Boston, when he visited PEDS during the Grand Rounds and Clinical Roundtable Discussions sponsored by the Guam UAP in October, 1995. Dr. Crocker indicated that for the type and quality of service that PEDS provided for infants with established disabilities and those at biological and environmental risk on Guam, PEDS was operating at a significantly high level of performance, given its resource limitations. The report of November 30, 1995, generated by Dr. Heidi Farra-San Nicolas which provided follow-up information from Dr. Allen Crocker's visit can be found in Appendix J. It includes the PEDS Evaluation summary of Dr. Crocker's visit.

## E. Future Directions of PEDS Development

At this writing, PEDS has many fiscal, physical, and staffing needs. Directions for expansion must take into consideration:

(1) What PEDS has accomplished in the past 9 years and importance of its work (which will become more significant when the stories gathered during parent interviews are presented)

(2) The implications of a 10% population growth rate over the next 10 years, the number of live births this growing population generates, and the fact that experience has shown us that 17% of the live birth population on Guam may have been served through PEDS. Planning should consider that in the next year alone, PEDS can anticipate anywhere from 600 - 1000 screenings, evaluations and referrals.

(3) The resources available to continue supporting PEDS,

(4) Methods of accountability for:

- (a) longitudinal outcomes for children and families,
- (b) comparisons between PEDS funding and the dollar amount of savings made in terms of need for later special education services,

(c) interagency collaboration, sharing, and cooperation.

(5) Prioritized needs for better utilization of resources.

It is important that those concerned with PEDS begin to view it not as an extenstion of any particular agency, at either the federal or local level, but a unit in and of itself that has survived because of Part H requirements and interagency effort. While problems have continued in this interagency effort, PEDS has survived because of the need for this type of service for famlies in Guam.

# V. Service Delivery of the PEDS Unit

## Introduction

This section will describe the PEDS service delivery model. It will illustrate how Guam is working toward a "seamless system of services" where agencies work collaboratively to support a family-focused service delivery system for early intervention. It describes the essential concepts and strategies that are essential in developing programs in early intervention. It concludes with stories gathered from parents interview on PEDS effectiveness, both strengths and weaknesses. Future planning should consider the need for recruitment in early intervention, the need to encourage research in Guam, and a awareness of issues which continue to create challanges in early intervention.

## A. The PEDS Service Delivery Model

Bowe (1995) describes a "seamless system" service model as follows:

> "seamless system is a term referring to a set of services that has no gaps or delays between Part H early intervention and Part B preschool services or other pre-kindergarten programs." (Bowe, 1995, pg. 16)

A key feature to a seamless system model is that a developmental approach is taken, one that seeks to avoid labeling a child between birth to five years. The focus is on the child's strengths and needs in the five developmental areas: cognitive, physical, communication, social, or emotional, and adaptive. Extensive parental input is sought at all levels and a method for continued monitoring and service is in place to support transitioning.

Exhibit 8 captures the service delivery model of "seamless" services that is place for Guam. Families make contact directly with Guam DOE-Division of Special Education, the lead agency or first contact is made often through the monitoring of infants born at GMHA. Other contact points are through Public Health nurses, self referral, and physicians. Physicians in private practice, military hospitals, or other government services make contact with PEDS through direct referral and at times the parent will also self refer to PEDS, through public awareness efforts. Once contact has been made, PEDS screens and assesses the child with all screening and assessment services available at the PEDS site. Whether the child is eligible or not, the parent is given information on the child and suggestions for developmental activities in all areas. If the child is at risk, monitoring procedures are initiated. If found eligible, a complete diagnostic workup is scheduled with the transdisciplinary team, which includes collaboration with the Infant/Toddler program. The interconnectedness of the transitioning team members builds in the assurance that eligible children will be given approriate service which often supports the family. Once eligibility is determined, Family Service Coordinators continue to provide support to the family though home-based visitations and/or center-based placement.

## B. Children and Families

There is no better measure of program effectiveness than information provided by the individuals the program was designed to assist. To gain insight from the parent's perspective, 5 parent/parents were interviewed. Parents were selected by the length of time they had made contact with PEDS. The first parents were a Chuukese family who had only recently made contact with PEDS (their infant was 2 months old), they were making their follow-up visit to PEDS after two home visits had been made, following discharge from GMHA. It was the families first contact with the PEDS facility. The second parent was a Filipino mother making a third return visit with her 4 month old infant. The third set of parents were a Chamorro couple with a 10 month old infant making a return routine visit to PEDS after their infant had been identified at birth at GMHA. The fourth parent was a single mother who was 15 years old at the time she gave birth, the infant was identified by PEDS through GMHA and was now 5 years old.

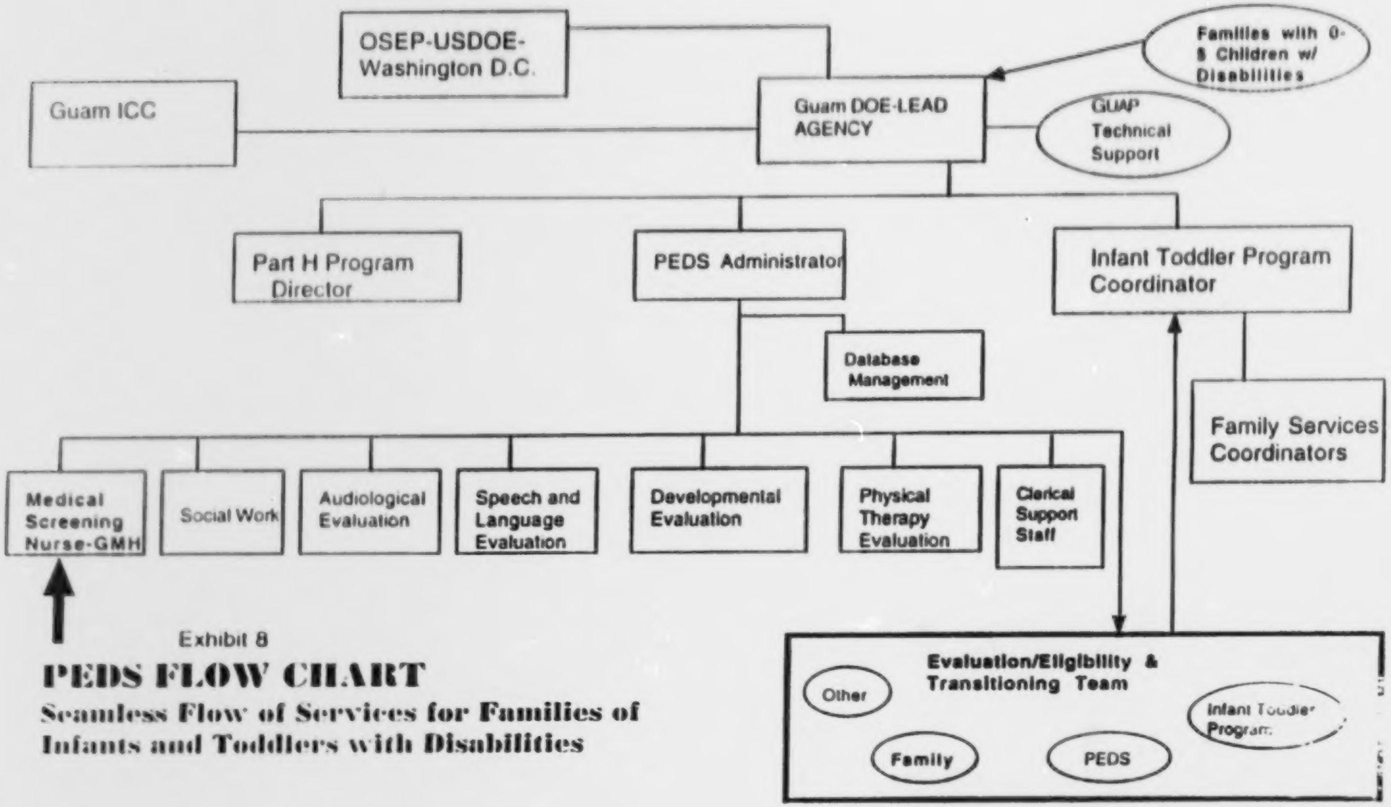


Exhibit 8

**PEDS FLOW CHART**

**Seamless Flow of Services for Families of Infants and Toddlers with Disabilities**

## 1. Parent Perception of PEDS

### a. The Chuukese Family

Both the mother and father came to PEDS for the infant's appointment, they were accompanied by their older child of 2 years and a female cousin who had transported them and was going to care for the toddler while the infant was being asssessed. After their appointment, the evaluator interviewed them regarding their satisfaction with PEDS services. The father was very careful about accompanying his wife, later it was clear that the mother spoke very little English and she relied on the father to translate. Both parents seemed very much at ease, this was noteworthy given that this was their first contact with PEDS. The father stated that their second child was born premature. The mother was interviewed by Rose Trebadini at the GMHA. The mother stated (through her husband) that when Rose told her about PEDS she was very grateful that she was living in Guam where her infant could get medical care. When asked how her home visit went, the mother indicated that things were going well and she enjoyed the ideas that have been suggested. When asked how she was able to communicate with the PEDS staff during home visits, the father stated he would always be there for visits so he can translate for his wife. When asked what would happen if he were not present and at work, he stated that he would always make it a point to be home when the visits are scheduled. When asked if there were any concerns about PEDS which they felt needed to be improved, both parents were very animated when stating that they had no problems with any of PEDS services. They have been so happy with the contacts that have been made. They felt very strongly that PEDS had helped them not only with their baby, but in making adjustments to having 2 children. The mother is trying to learn English but, she did not feel that language was a barrier.

These reports are in line with observations made by a PEDS staff member who was interviewed. The PEDS staff member indicated that Chuukese families were difficult to manage at times. There are often transportation problems in getting to PEDS or other appointments. When a home visit is scheduled with the mother, it is not unusual to have several adults or children standing around watching and listening, making open communication difficult, language barriers often compound the problem. Some Chuukese families do not believe that children should be immunized and often do not follow up on their appointments. The need to intervene and assist the family in understanding the importance of immunizations and to answer their concerns, so that they do not feel like their beliefs are being invalidated is often necessary.

### b. The Filipino Mother:

This mother had come to PEDS for follow up visits. She stated that she was not with her husband because he had to work. The infant had been born prematurely and first contact was made at GMHA. The mother stated that this was her first baby and when the Developmental Nurse screened her infant while she was still at GMHA, she felt a sense of relief at the reassurance that although her baby was born underweight, her baby would be monitored by PEDS. She indicated that she found the pamphlets, given by PEDS, to be very helpful in understanding what her baby was doing. She felt even stronger about the fact that she did not feel alone in dealing with the needs of her new infant. When asked if she would recommend PEDS to another mother, she stated, "Of course, I already have!"

As will be seen in the next story, the impact of first contact differs for some groups. While the transplanted Chuukese family and the new mother found the first contact to be a source of support, the Chamorro family had a different experience.

### c. The Chamorro Parents

This was a second marriage for the mother and a first child for the couple. The mother had another child from a previous marriage. Their child had been born premature. He weighed 3.7 lbs at birth. The mother made first contact with PEDS through the Developmental Nurse at GMHA, prior to her discharge. The mother stated that she did not like the way the Developmental Nurse approached her at the hospital. She stated she was "somewhat scared" when the Developmental Nurse kept using the term "disability" in relation to her baby. She felt that this was such a strong word to use. She became so concerned upon discharge that she talked with her doctor about the whether her baby was going to be disabled. Her doctor reassured her that the baby was doing well and that PEDS was a follow up program to help monitor her baby's progress and to learn things to assist her in the home. Once reassured by her physician, she felt more at ease. When the Family Service Coordinators made a home visit, she found them to be very supportive and reassured her that the baby would be fine. She stated that "their attitude and explanations were more comforting and they had a more 'we want to help' kind of an attitude. " She further stated that, "they made it our choice." whenever guidelines were given or there were options for services. Now the mother really appreciates the monitoring of the baby's progress. She would recommend PEDS to any parent because they helped them with guidelines, they "know their job and children" and they really appreciated knowing what to expect, because it prepared them to handle it. The mother felt that "the approach at the hospital needs improvement, because that first person contact give you a lasting impression." The mother stated that she really liked being informed about her baby's progress. She liked the fact that they could watch the testing and be shown what their baby could do. There were some things in the report that they felt were incorrect and they didn't like this. They felt that sometimes they were rushed and it was important for people to slow down and "smell the roses" because it takes time take to get to know things about a baby.

Prior to this interview, the evaluator shadowed the Developmental Nurse at GMHA to collect information on how first contacts were conducted. While this mother was clearly alarmed by the contact, her response is not unusual. Parents are highly sensitive after the birth of a child. When physical anomalies are present, the level of sensitivity is heightened. Best approaches to parents in this heightened state can be risky. Giving a completely optimistic view could be as misleading as a completely pessimistic view of potential outcomes. Finding the happy balance with parents is not always easy during this heightened state of concern. The parent's positive response to follow up and continued involvement in PEDS suggest that they value the benefits of early intervention and are willing to participate fully in improving services. What is of empirical interest is the reaction the parents had to first contact. It was completely opposite of the first sets of parents who made first contact at GMHA. Age, ethnicity, and marital history may be variables that affect attitudinal differences among Pacific island parents' first contact with early intervention service providers. Further research into these differences among Guam's ethnic groups may lead to different approach strategies used at first contact in hospital programs.

#### d. The Teen Mother

This young Filipino mother was 15 years old when she became pregnant. She was referred to PEDS by the FHP physician because of lack of prenatal care and maternal age. At the time of the interview for this report, she was 20 years old, enrolled in college, and her child was 5 years old and in Kindergarten. The mother's recollection of her PEDS experience was most impressive. She stated that she was "very scared to be a first time mother" and the PEDS staff helped her make a better adjustment. She read everything they gave her and was happy to have a place to go to where no judgements were made and information and support was readily offered. She stated that her first contact with PEDS was positive and she commented that the Developmental Examiner "...was really great." This former teen mother was very enthusiastic about sharing information on her child and their PEDS experience. She brought in copies of all reports from PEDS and gave permission that they be included in this report (see Appendix K). This teen mother is now a sophomore in college. She is training to become a teacher herself. Her daughter started Kindergarten and is doing exceptionally well.

### 2. Cultural Diversity Issues

In providing early intervention services to the wide diversity of Pacific island families, the need for greater cultural awareness is essential. If the families interviewed for this evaluation is any measure of PEDS performance, it seems clear that PEDS is needed, wanted, and appreciated, however refinement of approaches among different ethnic groups needs careful attention. Cohen & Spenciner (1994) state that:

> Children and families from diverse lingusitic and cultural backgrounds bring with them various cultural perspectives and values, knowledge of languages other than English, and attitudes about the roles and responsibilites of the family, educators, therapists, and early intervention specialists. In working with these children and their families, we must respect and appreciate the richness of languages and cultures that may be unfamiliar to us. (Cohen & Spenciner, 1994, pg. 33)

Developing "cultural competence" in Micronesian cultures requires that early intervention professionals:

- develop sensitivity to a family's linguistic and cultural background
- understand that misperceptions often lead to misunderstandings
- avoid stereotyping
- become familiar with and appreciate the family's culture, custom, and language
- handle conflicting cultural values in child management issues in a caring and positive manner by focusing on improved outcomes for the child, rather than making judgements about the culture
- share ideas which tend to have a positive effect in communicating with parents from cultures which are different from your own
- recognize that nonverbal behavior communicates louder than verbal behavior. Gestures, eye contact, and physical contact while communicating hasve different meanings from culture to culture.

### 3. Working with Families

The parent perceptions of PEDS in this evaluation continue to demonstrate that families are at various stages, in terms of how they view their role in early intervention programs. While the move toward more "family-centered" approaches are being promoted by early childhood special education programs, it is important to recognize that some families must be supported in taking a more active role in deciding what services would be delivered and how they will be provided. Many families in the Pacific islands are happily willing to let the professional team make all decisions on their behalf, in other cases, as in the Chamorro couple interviewed for this evaluation, they appreciate the opportunity to become involved in decision making. Families in the Pacific islands may need to be supported in learning family-centered approaches. Presenting families with choices and learning how to mentor families in making choices will develop more parent involvement and empower them.

### 4. Research on Outcomes

From its original conception, PEDS was designed to be a screening, assessment and referral center for infants and toddlers. In addition, it was envisioned that it would also become a training and research site for documenting outcomes of early intervention in Guam and in developing interdisciplinary training across disciplines. As of this writing, the College of Nursing and the College of Education have integrated PEDS into course practicums, observations, and internships. These are documented in the PEDS Annual Reports. Two students graduated within the Early Childhood Special Education graduate program, both having completed these focused on early intervention issues in Guam. The former PEDS Director developed and published a developmental screening instrument specifically for the Pacific islands, entitled: *Island Infant/Toddler Screening Instrument (IITSI)* which is now available nationally and is routinely used for screening in PEDS. One research article has been published on PEDS data, it is found in the *Micronesian Educator*, the UOG-College of Education journal, and is entitled: *Where America's Special Babies* Begin by June W. Holstrum (see Appendix L). The article described developmental outcomes of Guam's special care infants, looking at developmental outcomes of an identified group of infants and comparing their outcomes to mainland infants. Because the sample size was to small to make generalizations, preliminary results, "indicate that our smallest, sickest babies may have a higher mortality and morbidity rate than mainland babies." (Holstrum, 1992, pg. 53). Once PEDS re-establishes its database system, it is anticipated that more research in early intervention in Guam will be forthcoming. Bowe (1995) posed nine questions that continue to be major areas of research in early intervention research:

1. Is Early Childhood Special Education effective?
2. Is earlier better?
3. Is more intensive better?
4. Does parental involvement help?
5. Is Early Childhood Special Education cost-effective? Cost beneficial?
6. Does inclusion help children with disabilities?
7. Are we helping those most in need?
8. Does teaming work?
9. What should we teach?

The research agenda in early childhood special education as Bowe (1995) indicated has entered a second generation where research questions concerning the interactions between children and their families, intervention strategies, and goals and outcomes are the major focus. As Bowe further points out however, the value of research is that it provides us with reliable documentation of program effectiveness and in the design of individual service plans which assist us in determining how to structure more meaningful and effective ways to meet the needs of the child.

# VI. Recommendations: Interagency Initiatives & Future Directions

## Introduction

This section summarizes recommendations made throughout the PEDS evaluation process. It gives specific directions for improvement of PEDS goals and objectives and suggests immediate concerns requiring priority. It discusses the importance of having PEDS more fully adopt the seamless service delivery model, the need to continue to enourage research agendas, and it concludes with recommendations for the adoption of the self study evaluation process for Part H programs in Guam.

### A. PEDS Unit-Service Expansion

#### 1. Staffing Needs

As discussions on the development of PEDS continues, planning additional staff needs should be done with anticipated statistics for Guam in the coming years. As indicated earlier, a 10% population growth rate can be anticipated in the next 5 years, with 3% of that number representing live births on Guam. If PEDS is serving 17% of Guam's live births, PEDS staffing needs will need to correspondingly increase. Based on GMHA birth records from October, 1995 to July, 1996 the following annual figures were determined:

Average number of births per month: 299
299 x 12 months = 3,588 Projected annual births

Average number of births < 2500 grams per month: 19
19 x 12 months = 228 Projected annual SGA[1]

Average number of births requiring Intermediate Care (IC) per month: 61
61 x 12 months = 732 Projected annual IC infants

Average number of births requiring NICU Care per month:
7 x 12 months = 84 Projected annual NICU infants

Average number of birth resulting in death per month:
2 x 12 months = 24 Projected annual infant mortality

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[1] Small for gestational age

From these projections it is apparant that PEDS can anticipate continued increases for infants in need of service if population growth trends continue as it has in the last 5 years. At the current time, PEDS has identified the need for two full time positions and a physician consultant. These are immediate needs that would improve services at the present time. It is anticipated that there will be a need for a second Developmental Examiner in the near future and a Speech and Language Pathologist in the next 5 years.

### 2. Operating Procedures

The need for an updated version of a PEDS Policy and Procedures Manual is critical with anticipated staff turnover and the increase in the number of research and training activities which the future will bring as interdisciplinary programs are initiated.

Recruitment into the field of Early Chilhood Special Education at the graduate level is needed. It will be necessary to revive another cycle of the graduate program that was in place in 1988 in order to recruit local professionals. In line with this recommendation, GICC and the lead agency must make personnel preparation, licensure, and credentialing in Early Chilhood Special Education a top priority. The development of baseline competencies is essential.

PEDS can no longer wait for the development of an islandwide database system. Manual data collection will not motivate further research in the field. In addition, Part H calls upon states to "create a system for compiling data on the numbers of infants and toddlers with disabilities and their families in the State in need of appropriate early intervention services..." It is recommended that a system entitled Pro-Child be considered. This is a data management system targeted for Part H programs. It is recommended that a data system be put in place immediately. Consideration should be given to user friendliness of the system, needs of the PEDS data management needs, and capability of the system to interface with DPH&SS plans for a data management system.

Attention must be given to getting PEDS hooked up to an email system and access to the Internet, including the inclusion of a PEDS website. In addition, PEDS requires computer upgrades of their current system. Computer hardware acquisitions should be carefully planned into PEDS 5 year projection.

The collaboration between PEDS and the Infant/Toddler program is currently done on an "as needed" basis, primarily when there is a child requiring services or transitioning or if the teams come together for training. Collaboration needs to occur on a regularly scheduled basis, as well since, the teams have much to learn from each other in terms of developing relevant approaches to service provision. The PEDS Director, Part H Coordinator, and the Infant/Toddler program Coordinator need to meet and plan these monthly meetings annually so that service is not interrupted. In line with this recommendation, there is a need for ongoing staff development. The Developmental Nurse is in particular need of staff development in order to increase awareness of new assessment procedures for newborns and to learn best practice approaches in meeting new parents of high risk infants.

It is recommended that the lead agency make budget transfers to UOG to support PEDS a year ahead of schedule so that there is continuity for day to day operations and to alleviate the current problems with budget management. While funds are disbursed on an annual basis for Part H, local funding sources may be considered during the transition with reimbursement upon receipt of federal funds, if it is legally possible. The budget issues are currently at the root of many problems which PEDS faces.

### 3. Physical Plant

The current PEDS site has serious problems requiring immediate attention. The dominant need is to make the site accessible for individuals with disabilities. The second need is for planning for expansion. The current floor space can not adequately meet the needs of the current staff. Expansion plans and rennovations of the PEDS site is needed. The current staff requires, at minimum, 2400 square feet of floor space for therapy training and parent paraticipation and observation rooms.

### 4. Needs of Families Served

A major area of need is the expansion of public awareness of PEDS. Currently, PEDS puts out a directory of services for Early Intervention and two public awareness brochures to the community (see Appendix M). The need for other methods to promote awareness is essential. PEDS should consider negotiating with KGTF for the development of information spots to be televised periodically. The use of posters promoting PEDS at GMHA and private clinics and doctors' offices is another avenue to consider. PEDS should make it a point to put a story into the local newspaper, the Pacific Daily News to promote its successes. There are also sections of the PDNwhere PEDS meetings, announcements, and local accomplishements can be promoted. The development of a PEDS website is another way to develop public awareness.

Parent training programs for the birth to three population is needed to encourage parents to network with one another to share experiences and to help each other cope with a child at high risk or with a disability. Families in Guam have few resources to go to for emotional support. This recommendation can be initiated with DPH&SS or DMH&SS in promoting parent involvement.

### 5. Adoption of Service Delivery Model for PEDS

The PEDS policy and procedures manual should include a clear statement of the service model that it utilizes for families and the basic philosophies of PEDS. The need for a clear vision statement and plan for improvement is strongly recommended. The model recommended in this report may be adopted, revised, or considered so that all Part H programs have a sense of what seamless services entails.

### 6. Measures to Determine Progress

It is ill-advised to wait another 9 years before a second PEDS evaluation is completed. If the self-study evaluation process is adopted, GICC and the lead agency must monitor progress closely. It is recommended that GICC develop a system for determining progress made in serving infants and toddlers who are at risk or disabled. These measures should consider multiple sources for data collection and clear guidelines on how the data is to be summarized and presented.

## B. PEDS Unit-Research Directives and Initiatives

### 1. Publications on PEDS

The PEDS Director may want to consider working with the UOG College of Education in targeting one publication per year from PEDS to expand the knowledge base on the birth to three population in Guam. Collaboration with research faculty at COE or any other college will promote awareness and assist UOG faculty and students simultaneously.

### 2. Longitudinal Research on PEDS Outcomes

At the Part H meeting held in Washington D.C. , the evaluator was given the opportunity to participate in discussion on longitudinal research of Part H outcomes. This is a major concern of Part H programs throughout the United States. There are currently two research consortiums going among Part H programs that Guam should consider exploring, the efforts of a Utah consortium of Part H coordinators and a consortium of 20 states in California. The proposed Part H evaluation model from the Utah Evaluation Consortium is presented in Exhibit 9 and the evaluation instrument which will be used for qualitative data collection is presented in Exhibit 10. The names and addresses of the individuals involved follows these presentation.

Exhibit 9

# Proposed Part H Evaluation Model
# Utah Evaluation Consortium

Systems Change → Specific Services

Questions of evaluation will drive the evaluation process

## Key Questions in Part H Evaluation Systems:

Is Part H in your State a systems change effort?
How many programs are eligible under which category?
How many eligible are receiving services for specific category of children?
Is your State reaching children whom it was designed to serve?
Are services available for population identified?

Exhibit 10

## EVALUATION INSTRUMENT
### Data Collection Using Qualitative Strategies

Developmental gains &
Family Well Being → Are these our valued outcomes?

**Outcomes** ↔ **Strategies with finite Resources**
**Goals**
**Indicators**

*How are outcomes, goals and indicator different?*

Questions which must be asked continually:

Are children prepared for Kindergarten?
Are Families well adjusted?
Are children fully included?

**Part H Evaluation Consortium-UTAH**
(The national evaluation of Part H programs is very distinct from this consortium)
Presenters at Part H Meeting In Washington D.C.

Merle McPherson - Maryland
Maternal and Child Health Bureau
Room 18A27
5600 Fishers Lane
Rockville, MD 20857
Phone: (301)443-2350
FAX (301) 443-1719

Linda Goetze
Early Invention Research Institute
Utah State University
Logan, UT 84322-6580
Phone: (801)797-1172
Fax: (801)797-2019

Mark Innocenti
Early Intervention Research Institute
Utah State University
Logan, UT 84322-6580
Phone: (801)797-2006
Fax: (801)797-2019

Richard Roberts
Early Intervention Research Institute
Utah State University
Logan, UT 84322-6580
Phone: (801)797-3346
Fax: (801)797-2019
This is a consortium of 10 states working with a group in Utah.

**Part H Evaluation Consortium-CALIFORNIA**
Kathleen Hebbeler
Stanford Research Institute
600 Mockingbird Place
Davis, Ca. 95616
Phone (916)756-6126
Fax: (916) 576-2932

20 States participating in a Part H Longitudinal Study

## C. PEDS Unit-Evaluation: Self Study Directions and Initiatives

The self-study evaluation process recommended by OSEP-USDOE has significant implications for Part H programs in Guam. Self assessment is a powerful tool as it alleviates the apprehensions, anxieties, and ambivalence that outside evaluators bring to the assessment process. It promotes a sense of trust among those being evaluated because it allows participants to have a voice in the process and it gives every individual an opportunity to be an evaluator. The adoption of the OSEP-USDOE Self Study process is strongly recommended. The format of the self study process is more meaingful than the extensive number of surveys developed for use in the self study. Guam may want to modify the need for survey data collection and consider a combination of both survey and qualitative approaches for their self study. The Self Study Manager must be someone who staff members feel safe and comfortable communicating with-- this is essential. Data management must be well organized. During the process of the PEDS evaluation, an incredible amount of data was amassed yet, when the data reduction began, much of the information was unnecessary or inappropriate, however every piece of data added insight into some aspect of the evaluation process. The need for large samples of parents for further insights into effective service delivery is encouraged.

The completion of this evaluation was an experience which led to the insight that self study, even at the program level, is a continious process. Much more could have been included in the evaluation, other data that is indirectly related to the process could have added more insight, however, the need to be clear on what the evaluation process is designed to accomplish is very important. It is my hope that the information summarized here will help decision makers for PEDS plan programs which will benefit the birth to three population now and for the future.

Velma A. Sablan, Ph.D.
PEDS Self Study Manager

## References

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Spenciner, L.J. and Cohen, L.G. (1994). Assessment of Young Children. Longman, New York.

# APPENDICES

Ann Delgado
9:29 am.
COE
Dg
9/20/89

324

# University of Guam

## PERSONNEL ACTION

UOG No.: 564-90
Acct. No.: 3035-9-003 90

| | | | |
|---|---|---|---|
| Heidi E. Farra-San Nicolas | 2. SEX<br>F | 3. DATE OF BIRTH<br>6-24-60 | 4. SOCIAL SECURITY NO.<br>186-48-0092 |
| 5. ADDRESS( (Give Zip Code for Mailing Address)<br>College of Education | 6. PHONE | 7. MARITAL STATUS<br>Married | 8. CITIZENSHIP<br>U. S. |

| | | | |
|---|---|---|---|
| 9. NATURE OF ACTION<br>A. Non-Tenure Track, Part-Time Employee<br>B. Term., Non-Tenure Track, Part-Time | 10. DATE REQUESTED | 11. EFFECTIVE DATE<br>A. 8/28/89<br>B. 12/15/89 | 12. LEGAL AUTHORITY<br>Public Law 19-40 |

| FROM | | | | | TO | | | |
|---|---|---|---|---|---|---|---|---|
| B. Assistant Professor | | | | Position Title | A. Assistant Professor | | | |
| 13. P.R./S.L. | 14. STEP | 15. PER ANNUM/PER ACADEMIC YEAR | 16. PER HR. | Salary | 17. P.R./S.L. | 18 STEP | 19. PER ANNUM/PER ACADEMIC YEAR | 20. PER HR. |
| III | 5 | $29,676.00 | $20.61 | | III | 5 | $29,676.00 | $20.61 |
| College of Education | | | | College/Unit | Collegeof Education | | | |
| | | | | Section | | | | |
| | | | | Other Agency | | | | |
| | | | | Payroll Number | | | | |

| | | | | |
|---|---|---|---|---|
| 21. EMPLOYMENT CATEGORY | 22. EMPLOYMENT PERIOD From | To | 23. RETIREMENT PLAN<br>Y(I) | 24. INSURANCE PLAN |

SEP 21 1989

REMARKS: (NOTE) Personnel actions for Non-Academic Employees are subject to Post-Audit by the Civil Service Commision

To serve as acting director of CDSC, teach ED442 and write proposal for Special Education.
Total amount $29,676.00 × 10% = $2,967.60.

This EMPLOYMENT is subject to the approval of the President of the University and shall not be binding upon the University unless it is approved by the President. Approval by any University officer other than the President shall not constitute approval by the President and shall not bind the University to any obligation. This appointment is also subject to the offering and completion of the course based on sufficient student enrollment. SUBJECT TO AVAILABILITY OF FUNDS.

UOG CONTROLLER
SEP 20 '89

25. Dean / Director Robert A. Underwood Date: 9/15/89
26. Personnel Bennett Garcia Date: 9/19/89
27. Certifying Officer (If applicable) Cecil Cosmo Date:
28. Vice President Roy T. Tsuda Date: 9/21/89
29. President Date: 9/21/89
30. Retirement Office (If applicable) Date:
31. Chairman, Board of Regents N/A (Public Law 19-40) Date:
32. Employee Heidi E. Farra-San Nicolas Date: 10-12-89
33. Personnel Mary Ann Wegner Date: 10/12/89

DISTRIBUTION: ( ) Employee-WHITE Original ; ( ) U.G. Personnel Div. - PINK ; ( ) U.G. Business Office - BLUE ; ( ) College/Unit Head - GOLD
( ) Employee's Folder - YELLOW ; ( ) Civil Service Commission - GREEN ; ( ) Retirement Office - WHITE

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DOE - UOG

# MEMORANDUM OF AGREEMENT

This Agreement is made and entered into by and between the Department of Education, Division of Special Education (hereinafter referred to as DOE) and the University of Guam, College of Education, Department of Clinical and Human Services (hereinafter referred to as the University) for the mutual benefit of both agencies:

WHEREAS, the University is committed to the pre-service and inservice undergraduate and graduate training of teachers and other professionals working with young children:

WHEREAS, the DOE is mandated by federal and local law to identify, monitor and provide the delivery of services of handicapped children from birth to 21 years on Guam:

WHEREAS, these two government agencies are committed to enhancing and supporting all efforts to prevent disabilities and to assist other agencies in efforts to integrate the disabled into society:

WHEREAS, it is in the mutual interest of both agencies to provide systematic, coordinated, and comprehensive quality services to at-risk and handicapped young children and their families:

NOW THEREFORE, in consideration of the following and foregoing conditions, the two agencies agree to establish the CHILDREN'S DEVELOPMENTAL SERVICES CENTER (CDSC):

## I

THE DOE AGREES TO:

1. Participate with the University in the establishment and ongoing operation of the CDSC.
2. Subject to availability of funds, assign appropriate support personnel to work under the supervision of the CDSC director in fulfilling the goals and objectives of the CDSC.
3. Subject to availability, provide access of existing materials used in zero to five programs to the CDSC director.
4. Subject to availability of funds, provide assistance in funding additional necessary educational supplies, equipment and materials for the CDSC.
5. Secure University approval through the Director of the CDSC before making any structural changes to House #17 in the Dean's Circle.
6. Assist in maintaining appropriate security procedures to safeguard the houses and their contents and provide the CDSC director with keys and combinations to all existing and future locks in House #17
7. To arrange for transportation for children and their families when necessary.

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THE UNIVERSITY AGREES TO:

1. Participate with DOE in the establishment and ongoing operation of the CDSC.

2. Provide the use of Dean's Circle House #33 for the Guma Nene program and House #17 for the use of the CDSC on a full time basis for a period of three years from the date of this agreement, and options for a three year renewal in the Spring of 1991.

3. Provide a separate budget account for the CDSC within the UOG Business office. The CDSC director administers the funds with periodic monitoring by the COE Dean and the UOG Controller. Contributions to the CDSC made by government agencies, private institutions, corporations, or individuals will be made directly to this account. Any fees collected from clients or agencies or insurance for services provided by CDSC will be deposited to the CDSC account.

4. Provide necessary maintenance to the above mentioned houses both in routine upkeep, cleaning and emergency needs basis, including the provision of necessary rest room supplies.

5. Assign work-study students to the CDSC if requested by the CDSC director.

6. Utilize both sites for appropriate observation, practicum, teaching, and research sites for UOG training programs serving zero to five.

7. Provide basic utilities, including air conditioning and campus telephone lines for both houses.

8. Transfer existing Early Childhood Special Education (ECSE) materials, equipment, and supplies acquired through the ECSE grant to the CDSC.

9. Carry and maintain during the term of this agreement and any extensions thereof, comprehensive public liability insurance with limits of not less than $100,000 per person and $300,000 per occurrence as provided for under the University of Guam's general liability insurance coverage. This will include the rider to the insurance policy which protects against injury caused by food poisoning.

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IT IS MUTUALLY AGREED:

1. That the purpose of the CDSC is to provide the following services: identification/referral, screening, assessment for eligibility, monitoring, case management, facilitation of placement, facilitation of transition, and facilitation of intervention services. The CDSC is also to be used as a site for training and research.

2. To work with the Territorial Interagency Coordinating Council in future development of appropriate services to young children and their families.

3. The CDSC director is hired as a UOG employee by a selection committee composed of representatives from DOE and UOG. The title of the position is: Technical Assistant (Director, CDSC). It is a 12 month 1.0 FTE position. The selection committee is composed of three members from the University and three from DOE. Committee members are appointed by the Dean of the COE and the DOE Associate Superintendent of Special Education. The salary of the CDSC director is funded .50 by the University of Guam and .50 by the Department Of Education. These funds are identified and allocated by the Department of Education and the University of Guam under the administrative responsibility of the Dean of COE and the DOE Associate Superintendent of Special Education.

4. The CDSC director is responsible for the overall direction and accountability of the CDSC under the mutual administrative guidance of the Dean of COE and the DOE Associate Superintendent of Special Education. The director reports to the Dean of COE. Responsibilities of the CDSC Director include, but are not be limited to:

   a. Submission of an annual report to the Dean of COE and the DOE Associate Superintendent of Special Education which summarizes all budgetary and administrative activities of the CDSC.

   b. Submission of an annual report of the number of children served, type of services provided, referral sources, and referrals made.

   c. Preparation and submission of an annual request for funding for necessary supplies, equipment, and materials to operate the center.

   d. Submission of an annual report regarding the number of student practicums, internships, and special projects conducted at the CDSC or in which the CDSC serves as a resource.

   e. Maintenance of an inventory of materials, equipment, and supplies under the management of the CDSC. This includes material, equipment, and supplies donated by private individuals and organizations.

   f. Supervision and evaluation of UOG and DOE personnel assigned to the CDSC.

   g. Development and implementation of public awareness efforts.

   h. Coordinate the development of a five year plan for the CDSC congruent with the goals and objectives of the Early Childhood Special Education State Plan and utilizes the Territorial Interagency Coordinating Council for input.

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i. Maintenance of an infant high-risk registry and a monitoring system which insures confidentiality and tracks high-risk and disabled children.

3. The Territorial Interagency Coordinating Council will serve as the advisory council to the CDSC as stipulated in P.L 99-457.

4. Jointly and cooperatively operate the CDSC for the mutual benefit of the University and DOE in providing comprehensive and coordinated assessment services and facilitate intervention services to developmentally delayed and high-risk infants, preschool age children, and their families.

5. That the CDSC emphasizes, in addition to children's services, the training of college students and parents of children receiving services.

6. That basic changes in philosophy, goals, and practices may be modified only by mutual agreement of the two agencies based upon input from the Territorial Interagency Coordinating Council.

7. This agreement may be terminated by either agency upon 60-days written notice.

8. That this Memorandum of Agreement shall become effective immediately upon completion of the signatures of all parties and shall expire on August 31, 1991. It is understood that the parties are under no obligation to renew this agreement although they may agree to do so if the continuation of the CDSC serves the purposes which it has been designed to fulfill for the DOE, UOG, and the community at large and if conditions warrant renewal.

BEST COPY AVAILABLE

IN WITNESS THEREOF, the parties hereto have executed this Agreement on the dates indicated by their respective names;

FOR THE DEPARTMENT OF EDUCATION:

Rosa Salas Palo / 06/22/88
Rosa Palomo, Director / Date

Steve T. Spencer / 6/14/88
Steve Spencer, Associate Superintendent of Special Education / Date

FOR THE UNIVERSITY OF GUAM:

Roy T. Tsuda, Acting / 6/3
Wilfred Leon Guerrero, President / Dat

Robert Underwood / April
Robert Underwood, Dean, COE / Dat

APPROVED AS TO FORM:

/ 6/21/88
DOE Legal Counsel / Date

/ 5/3/88
UOG Legal Counsel / Date

/ 6-6-
J.U. TORRES, CHAIRMAN
BOARD OF REGENTS / Date

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## MEMORANDUM OF AGREEMENT

This agreement is made and entered into by and between the Guam Memorial Hospital (hereinafter referred to as GMH), the Children's Developmental Services Center (hereinafter referred to as CDSC), and the Department of Public Health and Social Services (hereinafter referred to a DPHSS) for the benefit of Guam's at risk, high risk, and handicapped infants, young children, and their families. (The CDSC is jointly sponsore and operated by the Department of Education, the University of Guam, and the Department of Public Health and Social Services).

WHEREAS, the GMH is committed to the finest of medical care for special infants and young children,

WHEREAS, the CDSC is committed to the early identification of developmental disabilities and related handicapping conditions,

WHEREAS, the DPHSS is committed to comprehensive health services for infants, young children, and their families,

WHEREAS, it is in the mutual interest of these agencies to provide systematic, coordinated, and comprehensive quality health and developmental services to at risk and handicapped young children and their families:

NOW THEREFORE, in consideration of the following and foregoing conditions, the identified agencies agree to establish a GMH/CDSC Developmental Follow-Up Program for Special Care Infants and Young Children.

I

THE GMH AGREES TO:

1. Cooperate with the CDSC and DPHSS in the establishment and ongoing operation of the Developmental Follow-up Program for at risk and handicapped infants and young children.
2. Grant the CDSC staff use of clinical facilities, provide orientation and make available materials needed for proper orientation of staff and students.
3. Include the referral to the CDSC for all, [illegible] eligible infants (as established in the attached proposal) in the routine treatment protocol for at risk infants and young children.
4. Participate in weekly developmental rounds in the special care nurseries and pediatric ward.
5. Provide the CDSC (with the parent's consent) [illegible] access to pertinent medical records.
6. Provide the CDSC (with the parent's consent) [illegible] a copy of the medical discharge summary for each infant referred for follow-up.

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7. Provide the CDSC staff space in the nursery area for storage of forms, protocols, folders and materials used in the Follow-up program.

8. Notify the CDSC director of any situation or behavior involving CDSC staff or student wherein safety of any person is threatened or whereby the cooperative intent of this agreement is jeopardized.

II

THE CDSC AGREES TO:

1. Assume responsibility for the planning and execution of the Developmental Follow-up Program for at risk and handicapped infants and young children. [illegible]

2. Coordinate with the GMH and DPHSS, UOG in the establishment and ongoing operation of the Developmental Follow-up Program.

3. Provide qualified staff who will be responsible for the developmental services as outlined in the attached proposal.

4. Provide copies of developmental summary reports of evaluations administered in the hospital for the hospital charts.

5. Provide the infant's primary care physician copies of developmental summary reports of all follow-up evaluations and recommendations.

6. Make available upon request and with the parent's consent medical, demographic, and developmental data for research purposes to appropriate professionals. If the research involves direct contact with patients or families, these professionals must submit a research proposal and all forms required by the Guam Committee on Human Research Subjects.

7. Be responsible for assigning students to work with the CDSC staff in the Developmental Follow-Up Program. The CDSC director will provide the GMH staff with a planned schedule of any student assignments, including dates, names of students, goals and objectives of the students.

8. Provide an orientation program for the staff of the GMH regarding the procedures, goal and objectives of the Developmental Follow-up Program.

9. Provide the identified agencies an annual report of the number of infants and young children served in the hospital and the number of children seen for follow-up at the CDSC.

10. Cooperate and coordinate with DPHSS in data collection.

11. Cooperate and coordinate with DPHSS for home visiting programs.

III

THE DPHSS AGREES TO:

1. Cooperate with GMH and the CDSC in the establishment and ongoi operation of the Developmental Follow-up Program for at risk a handicapped infants and young children.

2. Coordinate the collecting of data with the CDSC staff.

3. Coordinate the Home Care and District Nursing programs with th CDSC home visiting program.

IV

IT IS MUTUALLY AGREED:

1. That the purpose of the Follow-up Program is to provide early identification services for at risk and handicapped infants an young children.

2. Maintenance of positive relationships between the GMH and the CDSC shall be an ongoing process involving mutual exchange of information and continuous evaluation. A key factor in the evaluation shall be a bi-annual meeting of the CDSC director an staff and the GMH staff for the purpose of discussing mutual concerns, solving problems, and reporting on the number of infants and young children served.

3. The terms of this agreement will take affect upon approval and signatures of parties identified herein. The agreement will be reviewed annually. Modifications may be made upon mutual agreement of the identified agencies.

4. The agreement may be terminated upon 30 days written notificati by any of the identified agencies.

BEST COPY AVAILABLE

IN WITNESS THEREOF, the parties hereto have executed this Agreement on the dates indicated by their respective names;

FOR THE GUAM MEMORIAL HOSPITAL:

J Stadler MD / 6/14/90
James Stadler, M.S. Date
Chairman, Pediatrics

/ 6/14/90
Kenneth Sussman, M.D. Date
President, Executive Committee

/ 9/21/90
George Palican Date
Hospital Administrator

/
Date

Rosie R. Tainatongo / 9/21/90
Date
Chairperson, Board of Trustees

FOR THE DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES:

/ 10/31/90
Leticia V. Espaldon, M.D. Date
Director, DPHSS

E. Barrett-Anderson / 10/19/90
Attorney General Date

FOR THE CHILDREN'S DEVELOPMENTAL SERVICES CENTER:
(UOG and DOE)

/ 5/24/90
Wilfred Leon Guerrero Date
President, UOG

Donald R. Shuster / May 15, 19
Donald R. Shuster Date
Acting Dean, COE-UOG

W June Holstrum / 5/29/
W. June Holstrum Date
Director, CDSC

/ 5/22/9
UOG Legal Counsel Date

/ 6/5/9
Anita A. Sukola Date
Director of Education, DOE

Steve T. Spencer / 6/9/90
Steve Spencer Date
Associate Superintendent of Special Education, DOE

/ 6/9/90
DOE Legal Counsel Date

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# CHILDREN'S DEVELOPMENTAL SERVICES

## PROPOSAL FOR
## FOLLOW-UP OF HIGH RISK INFANTS
## AT GUAM MEMORIAL HOSPITAL

### INTRODUCTION:

Infants who experience neonatal difficulties are at greater risk for developmental disabilities. Families of these special care infants frequently have to cope with multiple stressors and are in need of continued support post discharge. The director and staff of the Children's Developmental Services Center (CDSC) propose the development and implementation of a longitudinal developmental follow-up program at Guam Memorial Hospital (GMH) for at-risk, high-risk, and handicapped infants and young children.

There are many reasons for follow-up programs for high risk infants. The primary reasons for the CDSC/GMH follow-up are:

1) Early identification and intervention of handicapped and at risk infants and young children will enhance their development and minimize their potential for developmental delay.
2) Post discharge support for the family will enhance the capacity of families to meet the needs of their special infants and young children.
3) Data collection will facilitate research designed to better understand the growth and development of special infants and those factors influencing growth and development. With better understanding, it is anticipated that improved services can be implemented.

### BACKGROUND:

For over 20 years, the federal government has been supporting research into the effectiveness of early intervention with handicapped and at risk young children and their families. These studies have demonstrated beyond doubt the economic and educational benefits of early intervention programs. In addition, the studies have shown that the earlier intervention is started, the greater is the ultimate dollar saving and the higher is the rate of educational attainment by these special children. Early intervention has had a significant impact on the whole family. The stress for the family of having a handicapped child is lessened and they are able to function more productively. Because of these results, children and families are more able to contribute to their community--indeed, early intervention can prevent the need for many costly services later in life.

Public Law 94-142, the 1975 Education of the Handicapped Act (EHA) ensured all handicapped children of a free public education. Public Law 99-457 (the 1986 amendment to the EHA) made it mandatory to provide handicapped preschoolers with special services and provided incentives for developing services for infants, birth through two years.

In response to PL 99-457 and because of a strong belief in the efficacy of early identification and intervention, the University of Guam, the Department of Education, and the Department of Public Health and Social Services are jointly sponsoring the Children's Developmental Services Center (CDSC). The CDSC offers comprehensive diagnostic and referral services for children between birth and five years of age. The primary purpose of the Center is to provide screening, diagnosis, and monitoring services for children who either are handicapped or are at risk for developmental handicapping conditions. The CDSC will also provide local and regional opportunities for professionals to engage in research, training, and collaborative exchanges of scholarly interests about the health, development, and education of infants, young children, and their families.

## PLAN OF ACTION:

The CDSC/GMH follow-up program will become a part of the routine protocol for the care of special babies at GMH. This includes both in-house and post discharge activities. The CDSC staff assigned to the follow-up program will consist of and Infant Development Specialist (IDS) and a Developmental Nurse (DN). The CDSC staff will work closely with the Public Health-Maternal and Child Health Nurse (MCHN) to implement the program. The IDS will be assigned to coordinate the health and developmental follow-up at GMH.

Enrollment Procedures: The IDS will daily check with nursery personnel, the DN, and/or the MCHN for information on all new admissions to the special care nurseries. The MCHN and/or the DN will fill out a risk register (CDSC 1.4) on each infant admitted and enter his/her name on the Follow-up log. They will then place a Referral Form (CDSC 1.5) in the infant's medical chart. Before an infant will be formally enrolled in the follow-up program, the referral form will be signed by the Nursery Physician.

Developmental Rounds: A core team will participate in developmental rounds. The rounds will include all infants and young children to be included in the follow-up. The team will consist of at least the Physician, the IDS and the Developmental Nurse (DN). It may also include the CDSC director, MCHN, Social Worker, or student intern assigned to the case.

The physician will explain each infant's medical complications, reason for admission, and any special equipment, procedures, or medication. As soon as the infant has stabilized, the physician will sign the referral form to the CDSC program which was placed in the infant's chart. The referral will signify that the baseline developmental exam may be administered. The physician will also notify the CDSC team when an infant is ready for discharge. Before discharge s/he will discuss any need for special home management plans such as home oxygen or special medications.

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Intake: After being notified by the physician that the infant is stable and the referral has been signed, the IDS, DN, or CDSC director will meet with the infant's family to explain the follow-up and obtain a signed consent (CDSC 1.6) to be included in the follow-up. The IDS, DN, or director will then fill out the intake form (CDSC 1.1) and administer a base line developmental exam. The Dubowitz Neurological Assessment of the Pre-term and Full-term Newborn Infants will be used.

Developmental Care in the Hospital: The IDS or DN will also meet with he family periodically while the infant is hospitalized to discuss the infant's developmental progress and to help the parents "read" their infant's cues. Parents will be taught to carefully observe their infant, to recognize signals of stress and pleasure and to respond accordingly. There will be an emphasis on the integration of the sensory system in order for the infant to become more receptive and responsive to his/her social environment. The amount, intensity, and type of stimulation provided will be contingent on the baby's response to the stimulation and his/her capacity to tolerate stimulation.

Population served: The target population for the Follow-up program will be all at-risk and handicapped infants. Specific criteria for referral include:

- -All infants admitted to the NICU (Neonatal Intensive Care Unit) and remaining there for more than three days
- -Infants weighing 2000 grams or less at birth,
- -Asphyxiated infants, defined as 5 minute Apgar of 6 or less
- -Respiratory Distress
- -Documented or suspected IVH
- -Neonatal seizures
- -Clinical evidence of central nervous system abnormality
- -Central Nervous System Infection
- -Hyperbilirubinemia (>20 mg/dl)
- -Hypoglycemia (Serum Glucose under 40 mg/dl)
- -Suspected visual or hearing impairment
- -SGA (<10% or LGA >90%)
- -Microcephaly (<10%) or Macrocephaly (>90%)
- -Hypo/hypertonia
- -Feeding problems
- -Persistent lethargy (>72 hours)
- -Multiple apneic episodes

At risk infants admitted to the NSCU (Neonatal Special Care Unit), well-baby nursery, or pediatric ward may be referred by a hospital staff physician. Risk status may be due to biological or environmental factors.

All infants meeting criteria will be placed on the high risk registry and be eligible for the follow-up program. An informed consent for follow-up and a release of information form will be obtained from the parents. The in-take form and the risk register will be completed before the infant is discharged.

Infants not meeting specific criteria, but referred by a physician will receive a developmental screening and intake before discharge. If follow-up is indicated, the infant will be added to the risk register.

Discharge from the Hospital: A copy of the medical discharge summary will be placed in the CDSC folder. Within two (2) days before discharge a developmental screening will be administered. The Newborn Developmental Screening (NBDS) will be used. The developmental discharge summary will be sent to the primary care physician and a copy will be included in the CDSC folder. The discharge summary will be reviewed with the primary care physician and will include the follow-up care plan. Infants with established risk will be referred for Special Education services. Before discharge, the IDS or DN will arrange with the family for a home visit two to four weeks post discharge.

Post Discharge Home Visit Follow-up: The nurse and one other CDS staff member will go on the home visit. During this visit:

-an informed consent must be signed, if not already obtained,
-a developmental screening will be administered
-a case history will be taken
-a health history and screening will be given
-family strengths, needs, and concerns will be identified
-the HOME scale will be completed
-an appointment will be scheduled at the CDSC for when the infant is three to four months of age.

The CDSC staff will coordinate the home visits with the Bureau of Community Health and Nursing Services at Public Health. Infants needing on-going skilled nursing home care will be referred to the Home Care program. Families needing more routine home visit follow-up will be referred to the District Nursing Program.

CDSC Follow-up: At the CDSC visit, an audiological exam and a developmental assessment will be administered. Infants who are developmentally age appropriate will be placed on a monitoring system. Their family will be given suggestions for activities and exercises to facilitate development. For infants who are suspected of being handicap or at risk and in need of special education services the assessment and referral procedures and forms for eligibility as outlined in the CDSC Handbook and the Handbook for the Delivery of Special Education Services will be followed. All infants will be scheduled to return to the CDSC for developmental follow-up at 8-9 months, 15 months, 2 years, and yearly after that until the child is five years of age. Age will be adjusted for prematurity until the evaluation at three years of age. A developmental summary report will be sent to the primary care physician after each visit. With the parent's permission, pictures of the infants will be taken and posted in the Center and at the NICU.

## TRAINING:

The CDSC, as a University of Guam facility, is also responsible for participating in the training of professionals and pre-professionals to work with infants and young children. The CDSC director will be responsible for overseeing any interns, observers, or practicum students who participate in the Developmental Follow-Up Program at GMH. Each student participant will be assigned to a CDSC staff member and will be supervised at all times. Each student participant will be required to attend a staff and student orientation. The CDSC director will provide the GMH staff with a list of students, their scheduled times at the hospital, and their major goals for participating in the Follow-up Program. Each student will be responsible for providing the GMH staff with a list of specific objectives of their practicum, internship, or observation.

## RESEARCH:

The CDSC staff will cooperate and collaborate with physicians and other professionals for research purposes. Data collected will be available for individual research projects. Care will be taken to insure confidentiality.

## SUMMARY:

The Children's Developmental Services staff is proposing a developmental follow-up program for at risk and handicapped infants and young children. We believe that through early identification and intervention the quality of life can be significantly enhanced for these special children and their families. We are looking forward to working with the GMH staff to provide a systematic, comprehensive follow-up program for Guam's special babies.

# CHILDREN'S DEVELOPMENTAL SERVICES

## PROPOSAL FOR
## FOLLOW-UP OF HIGH RISK INFANTS
## AT GUAM MEMORIAL HOSPITAL

### INTRODUCTION:

Infants who experience neonatal difficulties are at greater risk for developmental disabilities. Families of these special care infants frequently have to cope with multiple stressors and are in need of continued support post discharge. The director and staff of the Children's Developmental Services Center (CDSC) propose the development and implementation of a longitudinal developmental follow-up program at Guam Memorial Hospital (GMH) for at-risk, high-risk, and handicapped infants and young children.

There are many reasons for follow-up programs for high risk infants. The primary reasons for the CDSC/GMH follow-up are:

1) Early identification and intervention of handicapped and at risk infants and young children will enhance their development and minimize their potential for developmental delay.
2) Post discharge support for the family will enhance the capacity of families to meet the needs of their special infants and young children.
3) Data collection will facilitate research designed to better understand the growth and development of special infants and those factors influencing growth and development. With better understanding, it is anticipated that improved services can be implemented.

### BACKGROUND:

For over 20 years, the federal government has been supporting research into the effectiveness of early intervention with handicapped and at risk young children and their families. These studies have demonstrated beyond doubt the economic and educational benefits of early intervention programs. In addition, the studies have shown that the earlier intervention is started, the greater is the ultimate dollar saving and the higher is the rate of educational attainment by these special children. Early intervention has had a significant impact on the whole family. The stress for the family of having a handicapped child is lessened and they are able to function more productively. Because of these results, children and families are more able to contribute to their community--indeed, early intervention can prevent the need for many costly services later in life.

Public Law 94-142, the 1975 Education of the Handicapped Act (EHA) ensured all handicapped children of a free public education. Public Law 99-457 (the 1986 amendment to the EHA) made it mandatory to provide handicapped preschoolers with special services and provided incentives for developing services for infants, birth through two years.

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In response to PL 99-457 and because of a strong belief in the efficacy of early identification and intervention, the University of Guam, the Department of Education, and the Department of Public Health and Social Services are jointly sponsoring the Children's Developmental Services Center (CDSC). The CDSC offers comprehensive diagnostic and referral services for children between birth and five years of age. The primary purpose of the Center is to provide screening, diagnosis, and monitoring services for children who either are handicapped or are at risk for developmental handicapping conditions. The CDSC will also provide local and regional opportunities for professionals to engage in research, training, and collaborative exchanges of scholarly interests about the health, development, and education of infants, young children, and their families.

PLAN OF ACTION:

The CDSC/GMH follow-up program will become a part of the routine protocol for the care of special babies at GMH. This includes both in-house and post discharge activities. The CDSC staff assigned to the follow-up program will consist of and Infant Development Specialist (IDS) and a Developmental Nurse (DN). The CDSC staff will work closely with the Public Health-Maternal and Child Health Nurse (MCHN) to implement the program. The IDS will be assigned to coordinate the health and developmental follow-up at GMH.

Enrollment Procedures: The IDS will daily check with nursery personnel, the DN, and/or the MCHN for information on all new admissions to the special care nurseries. The MCHN and/or the DN will fill out a risk register (CDSC 1.4) on each infant admitted and enter his/her name on the Follow-up log. They will then place a Referral Form (CDSC 1.5) in the infant's medical chart. Before an infant will be formally enrolled in the follow-up program, the referral form will be signed by the Nursery Physician.

Developmental Rounds: A core team will participate in developmental rounds. The rounds will include all infants and young children to be included in the follow-up. The team will consist of at least the Physician, the IDS and the Developmental Nurse (DN). It may also include the CDSC director, MCHN, Social Worker, or student intern assigned to the case.

The physician will explain each infant's medical complications, reason for admission, and any special equipment, procedures, or medication. As soon as the infant has stabilized, the physician will sign the referral form to the CDSC program which was placed in the infant's chart. The referral will signify that the baseline developmental exam may be administered. The physician will also notify the CDSC team when an infant is ready for discharge. Before discharge s/he will discuss any need for special home management plans such as home oxygen or special medications.

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Intake: After being notified by the physician that the infant is stable and the referral has been signed, the IDS, DN, or CDSC director will meet with the infant's family to explain the follow-up and obtain a signed consent (CDSC 1.6) to be included in the follow-up. The IDS. DN, or director will then fill out the intake form (CDSC 1.1) and administer a base line developmental exam. The Dubowitz Neurological Assessment of the Pre-term and Full-term Newborn Infants will be used.

Developmental Care in the Hospital: The IDS or DN will also meet with he family periodically while the infant is hospitalized to discuss the infant's developmental progress and to help the parents "read" their infant's cues. Parents will be taught to carefully observe their infant, to recognize signals of stress and pleasure and to respond accordingly. There will be an emphasis on the integration of the sensory system in order for the infant to become more receptive and responsive to his/her social environment. The amount, intensity, and type of stimulation provided will be contingent on the baby's response to the stimulation and his/her capacity to tolerate stimulation.

Population served: The target population for the Follow-up program will be all at-risk and handicapped infants. Specific criteria for referral include:

- -All infants admitted to the NICU (Neonatal Intensive Care Unit) and remaining there for more than three days
- -Infants weighing 2000 grams or less at birth,
- -Asphyxiated infants, defined as 5 minute Apgar of 6 or less
- -Respiratory Distress
- -Documented or suspected IVH
- -Neonatal seizures
- -Clinical evidence of central nervous system abnormality
- -Central Nervous System Infection
- -Hyperbilirubinemia (>20 mg/dl)
- -Hypoglycemia (Serum Glucose under 40 mg/dl)
- -Suspected visual or hearing impairment
- -SGA (<10% or LGA >90%)
- -Microcephaly (<10%) or Macrocephaly (>90%)
- -Hypo/hypertonia
- -Feeding problems
- -Persistent lethargy (>72 hours)
- -Multiple apneic episodes

At risk infants admitted to the NSCU (Neonatal Special Care Unit), well-baby nursery, or pediatric ward may be referred by a hospital staff physician. Risk status may be due to biological or environmental factors.

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- -an informed consent must be signed, if not already obtained,
- -a developmental screening will be administered
- -a case history will be taken
- -a health history and screening will be given
- -family strengths, needs, and concerns will be identified
- -the HOME scale will be completed
- -an appointment will be scheduled at the CDSC for when the infant is three to four months of age.

The CDSC staff will coordinate the home visits with the Bureau of Community Health and Nursing Services at Public Health. Infants needing on-going skilled nursing home care will be referred to the Home Care program. Families needing more routine home visit follow-up will be referred to the District Nursing Program.

CDSC Follow-up: At the CDSC visit, an audiological exam and a developmental assessment will be administered. Infants who are developmentally age appropriate will be placed on a monitoring system. Their family will be given suggestions for activities and exercises to facilitate development. For infants who are suspected of being handicap or at risk and in need of special education services the assessment and referral procedures and forms for eligibility as outlined in the CDSC Handbook and the Handbook for the Delivery of Special Education Services will be followed. All infants will be scheduled to return to the CDSC for developmental follow-up at 8-9 months, 15 months, 2 years, and yearly after that until the child is five years of age. Age will be adjusted for prematurity until the evaluation at three years of age. A developmental summary report will be sent to the primary care physician after each visit. With the parent's permission, pictures of the infants will be taken and posted in the Center and at the NICU.

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The CDSC, as a University of Guam facility, is also responsible for participating in the training of professionals and pre-professionals to work with infants and young children. The CDSC director will be responsible for overseeing any interns, observers, or practicum students who participate in the Developmental Follow-Up Program at GMH. Each student participant will be assigned to a CDSC staff member and will be supervised at all times. Each student participant will be required to attend a staff and student orientation. The CDSC director will provide the GMH staff with a list of students, their scheduled times at the hospital, and their major goals for participating in the Follow-up Program. Each student will be responsible for providing the GMH staff with a list of specific objectives of their practicum, internship, or observation.

## RESEARCH:

The CDSC staff will cooperate and collaborate with physicians and other professionals for research purposes. Data collected will be available for individual research projects. Care will be taken to insure confidentiality.

## SUMMARY:

The Children's Developmental Services staff is proposing a developmental follow-up program for at risk and handicapped infants and young children. We believe that through early identification and intervention the quality of life can be significantly enhanced for these special children and their families. We are looking forward to working with the GMH staff to provide a systematic, comprehensive follow-up program for Guam's special babies.

# MEMORANDUM OF AGREEMENT

This agreement is made and entered into by the Department of Public Health and Social Services (DPHSS) with the CHILDREN'S DEVELOPMENTAL SERVICES CENTER (CDSC) for the benefit of Guam's at-risk, suspected and identified communication disordered persons:

WHEREAS, the DPHSS is committed to early detection of handicapping conditions that present risk of communication disorders among young children;

WHEREAS, the DPHSS is committed to providing audiological and speech-language evaluation services to all persons, regardless of age, who are in need of these services, or whose health maintenance capability is limited to Medicaid or Medically Indigent Program (MIP) assistance;

WHEREAS, the DPHSS is committed to enhancing and supporting all efforts to prevent disabilities and to assist other agencies in efforts to integrate the disabled into society; and

WHEREAS, the DPHSS believes that it is in the best interest of at-risk, suspected and identified young handicapped patients of the DPHSS to provide systematic, coordinated and comprehensive quality services to them and their families.

NOW, THEREFORE, in consideration of the following and foregoing conditions, the DPHSS agrees to participate in the CDSC:

THE DPHSS AGREES TO:

I

1. Transfer all audiological and speech-language pathology equipment (on loan basis only), supplies and related materials to the CDSC for use in the provision of hearing and speech diagnostic services.

2. Subject to availability of funds and personnel, assign the audiologist and speech-language pathologist supervisor, of the DPHSS Hearing and Speech Center, to continue their respective duties and responsibilities as defined by the Civil Service Commission job specification for their respective positions, including those delineated in the DPHSS Hearing and Speech Center's protocol for audiological and speech-language pathology services, at the CDSC site. Such duties may include providing in-service training to appropriate CDSC support staff who will be assisting in the provision of speech-language or audiological services.

3. Retain the positions and funding of salaries and fringe benefits for the audiologist and speech-language pathologist supervisor within the DPHSS budget for FY 1989, and FY 1990.

4. Subject to availability of funds, provide operational (supplies, materials, and contractual) support of the Hearing and Speech Center to the CDSC for the first fiscal year that this department participates in the CDSC operation.

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5. Allow personnel supervision of DPHSS personnel assigned to the CDSC by the CDSC director, as related to CDSC operations.

6. Allow the CDSC Director to develop in consultation with the Administrator of Bureau of Family Health Services, annual performance work plans and evaluations for the assigned DPHSS personnel, as related to their duties and responsibilities in the CDSC operations. These annual performance work plans and evaluations are subject to the concurrence of the Administrator of the Bureau of Family

7. Submit its specifications and requirements for the Hearing and Speech Center components of the CDSC.

8. Submit a complete set of DPHSS Directives and Policies pertaining to the DPHSS personnel assigned to the CDSC for their reference and compliance.

9. Submit an inventory of DPHSS Hearing and Speech Center equipment to be relocated (on a loan basis) to the CDSC.

## II

THE CHILDREN'S DEVELOPMENTAL SERVICES CENTER (CDSC) AGREES TO:

1. Provide audiological and speech-language evaluation services to all DPHSS patients, as needed and at no cost to the DPHSS or their patients.

2. Fully accommodate the requirements and specifications for test rooms and work space requirements for the DPHSS personnel assigned to the CDSC site.

3. Dismantle, as appropriate, and relocate speech and hearing equipment and materials to the CDSC site.

4. Provide funding and initiate necessary renovations to accommodate existing DPHSS speech and hearing equipment and materials.

5. Assume funding of all operational needs for all audiological and speech-language pathology equipment and materials at the conclusion of fiscal year 1989.

6. Submit all matters concerning the DPHSS employees assigned to the CDSC, that require the disposition of the Director of DPHSS by virtue of the GovGuam Civil Service Commission Personnel Rules and Regulations, to the DPHSS Director via the Administrator of the Bureau of Family Health Services.

7. Submit to the DPHSS Director, via the Administrator of Bureau of Family Health Services, Quarterly Reports on achievements and anticipated plans for DPHSS personnel, and statistics on accomplished diagnostic services by DPHSS personnel. Format to be determined by the DPHSS.

8. Provide a copy of audiological and speech-language evaluation reports, completed on DPHSS patients, to the DPHSS Medical Records Unit.

9. Carry and maintain during the term of this agreement and any extensions thereof, comprehensive public liability insurance with limits of no less than $100,000 per person and $300,000 per occurrence as provided for under the University of Guam's general liability insurance coverage. This will include the rider to the insurance policy which protects against injury caused by food poisoning.

10. Waive all claims to fees for audiology and speech-language pathology services collectable by the DPHSS Hearing and Speech Center as authorized by Executive Order 77-27. Any such fees due from third party payers will be billed and collected by the DPHSS and deposited into the General Fund account as authorized by the aforementioned executive order.

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## III

IT IS MUTUALLY AGREED:

1. That the purpose of the CDSC is to provide the following services: identification/referral, screening, assessment for eligibility, monitoring, case management, facilitation of placement, facilitation of transition, and facilitation of intervention services. The CDSC also is to be used as a site for training and research.

2. To work with the Territorial Interagency Coordinating Council in future development of appropriate services to young children and their families.

3. The CDSC Director is hired as a University of Guam employee by a selection committee composed of representatives from the Department of Education and the University of Guam. The title of the position is: Technical Assistant (Director, CDSC). It is a 12 month 1.0 FTE position. The selection committee is composed of three members from the University and three from DOE. Committee members are appointed by the Dean of the College of Education and the DOE Associate Superintendent of Special Education. The salary of the CDSC director is funded .50 by the University of Guam and .50 by the Department of Education. These funds are identified and allocated by the Department of Education and the University of Guam under the administrative responsibility of the Dean of COE and the DOE Associate Superintendent of Special Education.

4. The CDSC director is responsible for the overall direction and accountability of the CDSC under the mutual administrative guidance of the Dean of COE and the DOE Associate Superintendent of Special Education. The CDSC director reports to the Dean of COE. Responsibilities of the CDSC director include but are not limited to:

   a. Submission of an annual report to the Dean of COE, the DOE Associate Superintendent of Special Education, and to the DPHSS Director, which summarizes all budgetary and administrative activities of the CDSC.

   b. Submission of an annual report, a copy of which will be provided to the DPHSS Director, of the number of children served, type of services provided, referral sources, and referrals made.

   c. Insure that the DPHSS employees assigned to CDSC submit a quarterly report on a timely basis to the Director of DPHSS via the Administrator of Bureau of Family Health Services, in the format established by DPHSS for such reports.

   d. Submission of an annual report, a copy of which will be provided to the DPHSS Director, regarding the number of student practicums, internships, and special projects conducted at the CDSC or in which the CDSC serves as a resource.

   e. Maintenance of an inventory of materials, equipment, and supplies under the management of the CDSC. This includes materials, equipment, and supplies donated by private individuals and organizations, and materials, equipment and supplies relocated from the DPHSS Hearing and Speech Center.

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f. On-site personnel supervision and evaluation of DPHSS personnel assigned to the CDSC, as is necessary for the operations of the CDSC, but which are consistent with DPHSS policies and Civil Service Commission Personnel Rules and Regulations.

g. Ensure that time-keeping, leave (sick and annual) authorizations, and related personnel policies adopted by the CDSC, as applicable to the assigned DPHSS personnel to the CDSC, are in general compliance with DPHSS policies.

g. Development and implementation of public awareness efforts.

h. Coordinate the development of a five-year plan for the CDSC congruent with the goals and objectives of the Early Childhood Special Education State Plan and utilizes the Territorial Interagency Coordinating Council for input.

i. Ensure that the specific approved work plans delineated for the audiologist and speech-language pathologist supervisor, respectively, are accommodated and met by the appropriate DPHSS personnel assigned to the CDSC.

j. Maintenance of an infant high-risk registry and a monitoring system which insures confidentiality and tracks high-risk and disabled children.

k. Submission of the assigned DPHSS employees' time sheets, requests for leave of absence, and other personnel-related documents or forms, to the Administrator, Bureau of Family Health Services, DPHSS, on a timely basis.

5. The Territorial Interagency Coordinating Council will serve as the advisory council to the CDSC as stipulated in U.S. Public Law 99-457.

6. Cooperatively operate the CDSC for the mutual benefit of the University of Guam, Department of Education and the Department of Public Health and Social Services in providing comprehensive and coordinated assessment services and facilitate intervention services to developmentally delayed and high-risk infants, preschool age children, and their families, and all DPHSS referrals for audiological and speech-language diagnostic services.

7. That the CDSC emphasizes, in addition to children's services, the training of college students and parents of children receiving services, and continual audiology and speech-language pathology services to all DPHSS clients in need of the services, at no cost to either the DPHSS or the patients themselves.

8. That basic changes in philosophy, goals, and practices may be modified only by mutual agreement of the CDSC and DPHSS based upon input from the Territorial Interagency Coordinating Council.

9. That the terms of this Agreement may be revised or amended by mutual agreement as conditions or circumstances warrant.

10. This agreement may be terminated by either the CDSC or DPHSS upon 60 days written notice.

11. That this memorandum of Agreement shall become effective immediately upon completion of the signatures of all parties and

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shall expire on August 31, 1991. It is understood that the parties are under no obligation to renew this agreement although they may agree to do so if the continuation of the CDSC serves the purposes which it has been designed to fulfill as stipulated in this agreement and if conditions warrant renewal.

[END OF TERMS AND CONDITIONS.]

IN WITNESS THEREOF, the parties hereto have executed this Agreement on the dates indicated by their respective names:

**FOR THE DEPARTMENT OF EDUCATION:**

/ 1/20/89
ANITA A. SUKOLA, Director / Date
Department of Education

/ 1-12-89
STEVE SPENCER, / Date
Associate Superintendent of
Special Education

**FOR THE UNIVERSITY OF GUAM:**

12/20/8
WILFRED LEON GUERRERO / Date
President, University of Guam

Robert Underwood / 1/21/89
ROBERT UNDERWOOD, / Date
Dean, College of Education

FOR THE DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES:

/ 10/26/89
LETICIA V. ESPALDON, M.D. / Date
Director

Karen Cruz / 10/25/88
KAREN A. CRUZ / Date
Chief Public Health
Officer

APPROVED AS TO FORM:

1-30-89
Attorney General / Date

/ 1/15/89
DOE Legal Counsel / Date

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/
UOG Legal Counsel / Date

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# MEMORANDUM OF UNDERSTANDING
# CHILDREN WITH SPECIAL HEALTH NEEDS SYSTEMS MANAGEMENT PROJECT
# BUREAU OF FAMILY HEALTH AND NURSING SERVICES
# DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES
# AND
# PEDIATRIC EVALUATION AND DEVELOPMENTAL SERVICES (PEDS)
# COLLEGE OF EDUCATION
# UNIVERSITY OF GUAM

WHEREAS, both the Department of Public Health and Social Services and the Pediatric Evaluation and Developmental Services (PEDS) share a common goal of fostering the health and development of all 0-3 year old children with special health needs and their families; and

WHEREAS, both the Department of Public Health and Social Services and the Pediatric Evaluation and Developmental Services (PEDS) share a common goal of promoting the development and implementation of a territory-wide, coordinated and comprehensive, multi-disciplinary and interagency service delivery system with improved comprehensiveness, flexibility, accessibility, and responsiveness in meeting the needs of 0-3 year old children with special health needs and their families; and

WHEREAS, both the Department of Public Health and Social Services and the Pediatric Evaluation and Developmental Services (PEDS) recognize the fragmentation and gaps in service delivery, lack of resources, and the duplication of services as barriers to the attainment and provision of coordinated and comprehensive care for children with special health needs and their families; and

WHEREAS, both the Department of Public Health and Social Services and the Pediatric Evaluation and Developmental Services (PEDS) recognize that without a coordinated and comprehensive system of services, including service systems management, to assist in identification, and service linkages in the attainment and provision of care services, many of these children may not receive optimum health and medical care, as well as education and support services; and

WHEREAS, both the Department of Public Health and Social Services and the Pediatric Evaluation and Developmental Services (PEDS) recognize and agree that the development and implementation of service systems management, including an information management system, is essential to the development of a coordinated and comprehensive service delivery system for children with special health needs and their families; and

WHEREAS, the Department of Public Health and Social Services, Bureau of Family Health and Nursing Services, Maternal and Child Health Program, in compliance with the Interagency Agreement For The Provision of Early Intervention Services To Eligible Children Ages Birth Through Two Years and Their Families Under Public Law 99-457, entered into in September 1991, has assumed the responsibility of systems management for children with special health needs (including those who are eligible for Part H Services) ages birth through two years.

WHEREAS, the Pediatric Evaluation and Developmental Services, University of Guam, while maintaining its own data collection system for its specific needs, shall also support, maintain and expand systems management for Guam through reporting specific information to the Department of Public Health and Social Services thus undertaking responsibilities of "Reporting Service Provider" hereinafter set forth,

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NOW THEREFORE, the parties mutually acknowledge and agree to the following:

1. **The Children With Special Health Needs Systems Management Project, Bureau of Family Health and Nursing Services, Department of Public Health and Social Services shall establish a territory-wide information management system to include a Central Registry and related tracking activities that will:**

   1.1. **Ensure that all 0-3 year old children with special health needs are identified and registered while facilitating various tracking activities.**

   1.2. **Assess the number of 0-3 year old children with special health needs and selected diagnosed or suspected health/developmental risk conditions on Guam and in individual programs.**

   1.3. **Provide a coordinated interagency information management system to meet identified data needs of agencies providing services to 0-3 year old children with special health needs through the provision of periodic reports to the "Reporting Service Provider" from the CSHN Central Registry including both Service Provider-specific reports of children reported to the CSHN Central Registry and territory-wide aggregate data.**

   1.4. **Provide data on needs and resources to meet the needs of Guam for policy and program development for the elimination of gaps in the service delivery system.**

   1.5. Identify reported 0-3 year old children with special health needs requiring specialized medical/health assessments and collaborate for the provision of such services; and

   1.6. Facilitate continuous and appropriate services.

   1.7. Ensure that 90% of all 0-3 year old children with special health needs identified and enrolled and who are under the care of two or more service providers, have a designated care partner/service coordinator.

   1.8. Obtain feedback on the status of referrals.

   1.9. Facilitate agency/program case management activities.

   1.10. Document service utilization of 0-3 year old children with special health needs for planning, coordination, and advocacy.

2. The Pediatric Evaluation and Developmental Services, University of Guam, shall participate in the Children With Special Health Needs Systems Management Project as a "Reporting Service Provider" to the Central Registry in the manner indicated below.

   2.1. Designated personnel from the Pediatric Evaluation and Developmental Services (PEDS) shall complete and submit to the CSHN Systems Management Project the CSHN Central Registry Identification and Enrollment Form, upon identifying 0-3 year old children with special health needs eligible for enrollment in the CSHN Central Registry based on defined conditions and/or risk factors.

From Guam Memorial Hospital: The Pediatric Evaluation and Developmental Services (PEDS) Nurse or PEDS Infant Development Specialist shall complete and submit to the CSHN Systems Management Project the CSHN Central Registry Identification and Enrollment Form, upon identifying infants in Guam Memorial Hospital's Neonatal Special Care Unit and the Neonatal Intensive Care Unit eligible for enrollment in the CSHN Central Registry based on defined conditions and/or risk factors.

2.2. Designated personnel from the Pediatric Evaluation and Developmental Services (PEDS) shall obtain parental consent to enroll the child in the CSHN Central Registry using the CSHN Parent Consent Form, should the child be eligible for enrollment based on defined conditions and/or risk factors.

From Guam Memorial Hospital: The Pediatric Evaluation and Developmental Services (PEDS) Nurse or PEDS Infant Development Specialist shall obtain parental consent to enroll the child in the CSHN Central Registry and to monitor the child's growth and development through inclusion in the developmental Follow-up Program, co-sponsored by Guam Memorial Hospital and PEDS, using the CSHN Central Registry, GMH/PEDS Parent Consent Form.

2.3. Designated PEDS personnel shall, in the event parental consent is not obtained, complete the CSHN Central Registry Identification and Enrollment Form, providing only non-identifying, statistical data to be submitted to the CSHN Central Registry.

2.4. Designated personnel from the Pediatric Evaluation and Developmental Services, shall complete the CSHN Service Report Form I (Service Program Entry) for each child identified, reported, and enrolled in the CSHN Central Registry, specifically upon entry into programs/services provided by PEDS.

2.5. Designated personnel from the Pediatric Evaluation and Developmental Services, shall provide tracking information to the CSHN Central Registry on those identified and enrolled children with special health needs who are listed as their clients, or who have been referred to them based on reports received by the CSHN Central Registry. Tracking information will be submitted through the periodic completion of the CSHN Service Report Form II (Tracking) by designated PEDS personnel to the CSHN Central Registry.

2.6. The Pediatric Evaluation and Developmental Services, shall participate in the CSHN Systems Management Project territory-wide interagency service network, by ensuring the timely designation of a care partner/service coordinator for the identified and enrolled child (family), should the CSHN Central Registry receive reports indicating that the child is receiving services from two (2) or more providers, including PEDS, and should, based on care partner selection criteria, the proposed designated care partner be PEDS personnel.

This memorandum of understanding will become effective upon the signatures of the undersigned and will remain in effect until revoked or revised by either party.

Espaldon
LETICIA V. ESPALDON, M.D.
Director
Department of Public Health and
Social Services

Date Nov. 25, 1992

for John C. Salas, Acting
WILFRED LEON GUERRERO, Ed.D.
President
University of Guam

Date 11-27-92

John C. Salas
JOHN SALAS, Ph.D.
Academic Vice President
University of Guam

Date Nov. 27, 1992

Margaret A. Blaz
MARGARET BLAZ, Ph.D.
Acting Director
Pediatric Evaluation
Developmental Services
College of Education
University of Guam

Date Dec 3, 1992

DEPARTMENT OF ADMINISTRATION
DIVISION OF ACCOUNT.
Registration Date 12-14-92
Registered No. C36200067
Book No. 1
Registered By

Karen Cruz
KAREN CRUZ, M.P.H.
Chief Public Health Officer
Department of Public Health and
Social Services

Date 11/25/92

L. Duenas
LAURENT DUENAS, BSN,MPH,RN,CNA
Project Director
CSHN Systems Management Project
Administrator
Bureau of Family Health and Nursing
Services

Date 11/25/92

dc
RECEIVED
12/04/92

This is to certify to be a true copy of the original.

Oliva M. Pangelinan
OLIVA M. PANGELINAN
NOTARY PUBLIC
In and for the Territory of Guam
My Commission expires [illegible]

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# REVIEW OF MEMORANDUM OF AGREEMENT DATED OCTOBER 31. 1990 REGARDING A COMPREHENSIVE EARLY IDENTIFICATION OF AT RISK. HIGH RISK. AND HANDICAPPED INFANTS, YOUNG CHILDREN AND THEIR FAMILIES.

**Pediatric Evaluation and Developmental Services Center (PEDS)**
**House # 17 Dean's Circle**
**(formerly known as the Children's Developmental Services Center (CDSC)**

IN WITNESS THEREOF, the parties hereto have review ed the agreement dated Memorandum of Agreement (MOA) dated 10/31/90 (see attached) and have agreed to continue the MOA until November 1, 1997 or until such time that the PEDS Ad-hoc Advisory Committee drafts a new MOA approved by the respective agencies; and on the dates indicated by their respective names, the parties hereby extend the attached MOA .

FOR THE DEPARTMENT OF EDUCATION

Joseph L. De Torres, Ph.D.
Director of Education

Date: 12-18-95

Vince Leon Guerrero
Associate Superintendent

Date: 12/13/95

FOR THE UNIVERSITY OF GUAM

John C. Salas
John C. Salas, Ph.D.
President

Date: 11/30/95

James L. Craig, Ph.D.
Dean, College of Education

Date: 11/29/95

Margaret Blaz
Margaret Blaz, Ph.D.
Acting Director, PEDS

Date: 11/28/95

FOR THE DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES

Dennis Rodriguez ⓒ
Director of Public Health

Date:

Charles Crisostomo, M.P.H.
Acting Chief Public Health Officer

Date: 12/4/95

FOR THE GUAM MEMORIAL HOSPITAL ADMINISTRATION

Helen B Ripple
Helen Ripple, R.N.
Hospital Administrator

Date: 11/27/95

Date:

## MEMORANDUM OF AGREEMENT

This agreement is made and entered into by and between the Guam Memorial Hospital (hereinafter referred to as GMH), the Children's Developmental Services Center (hereinafter referred to as CDSC), and the Department of Public Health and Social Services (hereinafter referred to as DPHSS) for the benefit of Guam's at risk, high risk, and handicapped infants, young children, and their families. (The CDSC is jointly sponsored and operated by the Department of Education, the University of Guam, and the Department of Public Health and Social Services).

WHEREAS, the GMH is committed to the finest of medical care for special infants and young children,

WHEREAS, the CDSC is committed to the early identification of developmental disabilities and related handicapping conditions,

WHEREAS, the DPHSS is committed to comprehensive health services for infants, young children, and their families,

WHEREAS, it is in the mutual interest of these agencies to provide systematic, coordinated, and comprehensive quality health and developmental services to at risk and handicapped young children and their families:

NOW THEREFORE, in consideration of the following and foregoing conditions, the identified agencies agree to establish a GMH/CDSC Developmental Follow-Up Program for Special Care Infants and Young Children.

### I

THE GMH AGREES TO:

1. Cooperate with the CDSC and DPHSS in the establishment and ongoing operation of the Developmental Follow-up Program for at risk and handicapped infants and young children.
2. Grant the CDSC staff use of clinical facilities, provide orientation and make available materials needed for proper orientation of staff and students.
3. Include the referral to the CDSC for all eligible infants (as established in the attached proposal) in the routine treatment protocol for at risk infants and young children.
4. Participate in weekly developmental rounds in the special care nurseries and pediatric ward.
5. Provide the CDSC (with the parent's consent) access to pertinent medical records.
6. Provide the CDSC (with the parent's consent) a copy of the medical discharge summary for each infant referred for follow-up.

7. Provide the CDSC staff space in the nursery area for storage of forms, protocols, folders and materials used in the Follow-up program.

8. Notify the CDSC director of any situation or behavior involving CDSC staff or student wherein safety of any person is threatened or whereby the cooperative intent of this agreement is jeopardized.

II

THE CDSC AGREES TO:

1. Assume responsibility for the planning and execution of the Developmental Follow-up Program for at risk and handicapped infants and young children.

2. Coordinate with the GMH and DPHSS in the establishment and ongoing operation of the Developmental Follow-up Program.

3. Provide qualified staff who will be responsible for the developmental services as outlined in the attached proposal.

4. Provide copies of developmental summary reports of evaluations administered in the hospital for the hospital charts.

5. Provide the infant's primary care physician copies of developmental summary reports of all follow-up evaluations and recommendations.

6. Make available upon request and with the parent's consent medical, demographic, and developmental data for research purposes to appropriate professionals. If the research involves direct contact with patients or families, these professionals must submit a research proposal and all forms required by the Guam Committee on Human Research Subjects.

7. Be responsible for assigning students to work with the CDSC staff in the Developmental Follow-Up Program. The CDSC director will provide the GMH staff with a planned schedule of any student assignments, including dates, names of students, goals and objectives of the students.

8. Provide an orientation program for the staff of the GMH regarding the procedures, goal and objectives of the Developmental Follow-up Program.

9. Provide the identified agencies an annual report of the number of infants and young children served in the hospital and the number of children seen for follow-up at the CDSC.

10. Cooperate and coordinate with DPHSS in data collection.

11. Cooperate and coordinate with DPHSS for home visiting programs.

## III

THE DPHSS AGREES TO:

1. Cooperate with GMH and the CDSC in the establishment and ongoing operation of the Developmental Follow-up Program for at risk and handicapped infants and young children.
2. Coordinate the collecting of data with the CDSC staff.
3. Coordinate the Home Care and District Nursing programs with the CDSC home visiting program.

## IV

IT IS MUTUALLY AGREED:

1. That the purpose of the Follow-up Program is to provide early identification services for at risk and handicapped infants and young children.
2. Maintenance of positive relationships between the GMH and the CDSC shall be an ongoing process involving mutual exchange of information and continuous evaluation. A key factor in the evaluation shall be a bi-annual meeting of the CDSC director and staff and the GMH staff for the purpose of discussing mutual concerns, solving problems, and reporting on the number of infants and young children served.
3. The terms of this agreement will take affect upon approval and signatures of parties identified herein. The agreement will be reviewed annually. Modifications may be made upon mutual agreement of the identified agencies.
4. The agreement may be terminated upon 30 days written notification by any of the identified agencies.

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IN WITNESS THEREOF, the parties hereto have executed this Agreement on the dates indicated by their respective names;

**FOR THE GUAM MEMORIAL HOSPITAL:**

J Stadler MD, 6/14/90
James Stadler, M.S. Date
Chairman, Pediatrics

6/14/90
Kenneth Sussman, M.D. Date
President, Executive Committee

9/21/90
George Palican Date
Hospital Administrator

Date

Rosie R. Tainatongo, 9/21/90
Date
Chairperson, Board of Trustees

**FOR THE DEPARTMENT OF PUBLIC HEALTH AND SOCIAL SERVICES:**

Espaldon, 10/31/90
Leticia V. Espaldon, M.D. Date
Director, DPHSS

E. Barrett-Anderson, 10/19/90
Attorney General Date

**FOR THE CHILDREN'S DEVELOPMENTAL SERVICES CENTER:**
**(UOG and DOE)**

5/24/90
Wilfred Leon Guerrero Date
President, UOG

Donald R. Shuster, May 15, 199
Donald R. Shuster Date
Acting Dean, COE-UOG

W Jane Holstrum, 5/29/
W. Jane Holstrum Date
Director, CDSC

5/22/
UOG Legal Counsel Date

6/5/
Anita A. Sukola Date
Director of Education, DOE

Steve T. Spencer, 6/9/90
Steve Spencer Date
Associate Superintendent of Special Education, DOE

6/9/90
DOE Legal Counsel Date

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## III

THE DPHSS AGREES TO:

1. Cooperate with GMH and the CDSC in the establishment and ongoing operation of the Developmental Follow-up Program for at risk and handicapped infants and young children.

2. Coordinate the collecting of data with the CDSC staff.

3. Coordinate the Home Care and District Nursing programs with the CDSC home visiting program.

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5. Provide the CDSC (with the parent's consent) access to pertinent medical records.
6. Provide the CDSC (with the parent's consent) a copy of the medical discharge summary for each infant referred for follow-up.

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PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## Intake Information

Peds No: Name: Date:

DOB: Age: Sex:

Enrolled in Preschool Program: In Special Education Program:

If yes, name of program:

---

Mother's Name: Work Phone:

Father's Name: Work Phone:

Home Address:

Mailing Address:

Home Phone:

---

Ethnicity:

Child:

Mother:

Father:

Child's Primary Language:

---

Insurance:

Physician/Clinic:

PEDS Intake Form

| EDS<br>o. | NAME<br>DOB: | N/F | DOT | HEAR | S-L | DEV | PT<br>Dx | PT<br>Rx | HOSP<br>GMH/HV | ELIG | RC DATE |
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PEDS Manual
Database

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**Division of Special Education**
Guam Public School System

**Date:** ____________

## Referral for Services SPF 2.5

| | | |
|---|---|---|
| Name of Student Referred *(Last, first, middle)* | Sex: | DOB |

| | | | |
|---|---|---|---|
| School | School Code | Grade | Ethnic Code |

| | |
|---|---|
| Name of Referring Individual | Position/Title |
| CRT | CRT Code # |

Is this child presently receiving Special Education Services?
☐ Yes **Program:** ☐ No

| | |
|---|---|
| English Proficiency Code | Primary Language Code |

Reason for Referral: *See attached copies of Teacher Intervention Checklist (TIC) and Summary of Staffing (SOS)*
** Checklist Required*

**Referral Areas:**

☐ Academics SE
☐ Speech/Language * IS
☐ Hearing * IH
☐ Vision * IV
☐ OT *
☐ PT *
☐ Adaptive PE * AP
☐ Severe Emotional Problems * EH
☐ Community Based Education (CBE) RO
☐ Triannual Reevaluation TR Date Due: ________
☐ TR Speech only

| | |
|---|---|
| Date of **Vision Screening** | Results |
| Date of **Hearing Screening** | Results |

Parent Names

Home Address

Mailing Address

| | |
|---|---|
| Home Phone | Work Phone/s |

**This section to be completed by Special Education Data Control Clerk**

| | | | |
|---|---|---|---|
| Student Number | Status | Case Assigned to | Code |
| Assessment assigned to: | Assessment assigned to: | Reviewed/Assigned By | Date |

| **This section is to be completed by individual conducting assessment.** | | **This section is to be completed by individual assigned to the case.** | |
|---|---|---|---|
| Assessment Date | Assessment Date | Referral Area | Referral Area |
| Completed By / Code | Completed By / Code | Date of IEP | Date of IEP |
| Referral Area | Referral Area | Referral Action<br>☐ Yes<br>☐ No | Referral Action<br>☐ Yes<br>☐ No |

WHITE Special Education • YELLOW School • PINK Psych Services

**Division of Special Education**
Guam Public School System

## Committee Member Notification - SPF 3.2

**Date:** ____________________

Student: ________________________________________ DOB: __________ Grade: ___ School: ______________

☐ Principal or Administrator
☐ Assistant Principal
☐ CRT (Consulting Resource Teacher)
☐ School Guidance Counselor
☐ School Health Counselor
☐ Psychologist
☐ Speech/Language Therapist
☐ Vision Specialist
☐ Social Worker
☐ DVR Representative
☐ Student

☐ Hearing Specialist
☐ EH Representative
☐ OT (Occupational Therapist)
☐ PT (Physical Therapist)
☐ Leisure Ed Services
☐ Home Tutoring Services
☐ Homebound Services
☐ Headstart Representative
☐ Preschool Representative
☐ Infant Toddler Service Coordinator
☐ ____________________

☐ Regular Class Teacher/s
________________________________
________________________________
________________________________
________________________________
________________________________
☐ Resource Room Teacher/s
________________________________
________________________________
________________________________
☐ ____________________

You are invited to participate in an:

☐ Eligibility Meeting
☐ Initial IEP Meeting
☐ IEP Review Meeting
☐ IEP Review/Transition Meeting (age 14 & up)
☐ Reevaluation Meeting
☐ Initial IFSP Meeting
☐ IFSP Transition Meeting
☐ IFSP Review Meeting
☐ ____________________

This meeting is being held for the student identified above :

Date: ________________________________
Time: ________________________________
Location: ____________________________

(If necessary) Meeting rescheduled for:

________________________________
________________________________
________________________________

Please come to the meeting prepared to share information you have regarding this student, along with written documentation supporting your concerns and recommendations. *(You may use form SPF 4.2.2 and feel free to provide additional documents).* If you cannot attend the meeting, please let the CRT or Service Coordinator know and provide your input in writing *(file in either the Pending File or the student's file)* prior to the scheduled meeting.

**Division of Special Education**
Guam Public School System

Date ________________

## Parent Meeting Notification - SPF 4.1

| | | | |
|---|---|---|---|
| Name | DOB | Grade | School |

Dear Parents:

Your child may be/is eligible to receive special education and related services. We would like to invite you to attend a meeting scheduled for:

| | | |
|---|---|---|
| Date: | Time: | Location: |

We will discuss your child's eligibility and, if eligible, develop an:

☐ **IEP - Individual Education Plan** ☐ **IFSP - Individual Family Services Plan**

☐ Conduct an IEP or IFSP Meeting and/or Review and determine if there is a need for any change in your child's educational program.

☐ Discuss your child's reevaluation and continued eligibility, as well as review your child's IEP and determine if there is a need for change in the education program.

☐ Review your child's IEP or IFSP and discuss his/her Transition needs.

The following individuals have been invited to this meeting:

☐ Principal
☐ School Psychologist/Evaluators
☐ CRT
☐ General Classroom Teacher
☐ Special Education Teacher
☐ Counselor
☐ ____________________

☐ Speech/Language Therapist
☐ Health Counselor / Nurse
☐ Assistant Principal
☐ Vision or Hearing Specialist
☐ PEDS Representative
☐ IT Service Coordinator
☐ ____________________

☐ Headstart Representative
☐ Preschool Representative
☐ Occupational or Physical Therapist
☐ Social Worker
☐ DVR Representative
☐ Student
☐ ____________________

We encourage your attendance at this meeting. **If the date/time is not convenient**, or if you have any questions, please contact the school CRT at ______________________________ to arrange a more convenient time.

Sincerely,

CRT or Service Coordinator ______________________________

Principal/Administrator ______________________________

Please sign and return the original copy as soon as possible.

☐ Yes, I will attend this meeting
☐ I waive my right to 10 day notification.
☐ No, I cannot attend this meeting. You may conduct the meeting without me and send me copies of the results.

Signature of Parent or Guardian ______________________________

Date ______________________________

WHITE: Special Education • YELLOW: School/Child's Folder • PINK: Parents

Division of Special Education

Guam Public School System

# Parent Rights

## As guaranteed by the Individuals with Disabilities Education Act (IDEA)

*An explanation of Procedural Safeguards Available to Parents of Children with Disabilities.*

As a parent of a child with a disability, IDEA guarantees you specific due process procedures. Please read these rights. If you have questions or need further explanations, please call the Division of Special Education at 475-0549.

### *Prior Notice to Parents*

Your school district must provide you with written notice each time it proposes or refuses to initiate or change the identification, evaluation or educational placement of your children or the provision of a free appropriate public education to your child. This notice must include:

- A full explanation of all procedural safeguards available to you
- A description of the action proposed or refused by the district; an explanation of why the agency proposes or refuses to take the action; and a description of any options the district considered and the reasons those options were rejected.
- A description of each evaluation, procedure, test, record, or report the district used as a basis for the proposal or refusal; and
- A description of any other factors that are relevant to the proposal or refusal.

The notice must be written in language understandable to the general public, and ***provided in your native language*** or other mode of communication, unless it is clearly not feasible to do so. If your native language or other mode of communication is not a written language, your district must take steps to insure that the message is transmitted orally; or by other means in your native language or other modes of communication; that you understand the content of the notice, and that there is written evidence that these requirements have been met.

### *Parent Consent*

Your district ***must obtain your consent*** before conducting preplacement evaluation or initial placement of your child in a programs providing special education and related services. If you refuse to give consent, the district may use federal procedures for due process hearings to determine whether your child may be evaluated or initially provided special education or related services without your consent.

If the hearing officer upholds the school district, it may evaluate or initially provide special education and related services to your child without your consent, subject to your rights to appeal the decision and have your child remain in his or her present educational placement during the time pending any administrative or judicial proceeding.

Except for evaluation and initial placement, parental consent may not be required as a condition of benefit to you or your child.

### *Independent Education Evaluation*

You have the right to an independent education evaluation of your child. You have the right to an independent educational evaluation at public expense if you disagree with an evaluation obtained by your district. However, the district may initiate a due process hearing to show that its evaluation is appropriate.

If the final decision is that the evaluation is appropriate, you still have the right to an independent evaluation, but not at public expense. If parents obtain an independent educational evaluation at private expense, the results of the evaluation must be considered by your district in any decision made with respect to the provision of a free appropriate public education to your child, and may be presented as evidence at a due process hearing regarding your child.

If a hearing officer requests an independent educational evaluation as part of a hearing, the cost of the evaluation must be at public expense.

The district must provide you, upon request, with information about where an independent educational evaluation may be obtained.

Whenever an independent educational evaluation is at public expense, the criteria under which the evaluation is obtained, including the location of the evaluation and qualifications of the examiner, must be the same as the criteria the public agency uses when it initiates an evaluation.

### *Impartial Due Process Hearing*

You or a public agency may initiate a hearing regarding the public agency's proposal or refusal to initiate or change the identification, evaluation, or educational placement of your child or the provision of a free appropriate public education to your child.

The hearing will be conducted by the public agency directly responsible for your child's education.

The public agency must inform you of any free or low-cost legal and other services available in the area of you request the information, or you or the agency initiate a due process hearing.

A hearing may not be conducted by a person who is an employee of a public agency which is involved in the education or care of your child, or by any person having personal or professional interest which would conflict with his or her objectivity in the hearing. ( A person who otherwise qualifies to conduct a hearing is not an employee of the agency solely because he or she is paid by the agency to serve as a hearing officer.)

Each public agency shall keep a list of the persons who serve as hearing officers. The list must include a statement of the qualifications of each of these persons.

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The public agency shall ensure that a final hearing decision is reached and mailed to the parties within 45 days after the receipt of a request for a hearing unless the hearing officer grants a specific extension at the request of either party.

The decision made in a due process hearing is final, unless a party files a civil action under the procedures described below.

### *Due Process Hearing Rights*

Any party has a right to the following:

- Be accompanied and advised by counsel and by individuals with special knowledge or training with respect to the problems of children with disabilities
- Present evidence and confront, cross-examine, and compel the attendance of witnesses.
- Prohibit the introduction of any evidence at the hearing that has not been disclosed to that party at least five days before the hearing.
- Obtain a written or electronic verbatim record of the hearing.
- Obtain written findings of fact and decision. (After deleting any personally identifiable information, the public agency shall transmit those findings and decision to the state advisory panel and make them available to the public.)

You must be given the right to have your child present and to open the hearing to the public.

Each hearing must be conducted at a time and place which is reasonably convenient to you and your child.

### *Civil Action*

Any party aggrieved by the findings and decision made in a hearing has the right to bring a civil action in Territorial or Federal Court.

### *Child's Status During Proceedings*

During the pending status of any administrative or judicial proceeding regarding a complaint, unless you and your district agree otherwise, your child must remain in his or her present educational placement. If the hearing involves an application for initial admission to public school, your child, with your consent, must be placed in the public school program until the completion of all the proceedings.

### *Award of Attorney Fees*

In any action brought under Part B of the Individuals with Disabilities Education Act, the court may award reasonable attorney fees to the parents or guardians of a child or youth with disabilities who is the prevailing party.

### *Surrogate Parents*

Each public agency shall ensure that an individual is assigned to act as a surrogate for the parents of a child when no parent can be identified; the public agency, after reasonable efforts, cannot discover the whereabouts of a parent; or the child is an ward of the Territory under the laws of the Territory. The agency must have a method for determining whether a child needs a surrogate parent, and for assigning a surrogate par to the child.

The public agency may select a surrogate parent in any way permitted under Territorial law, but must ensure that a per selected as a surrogate parent is not an employee of a publi agency which is involved in the education or care of the child, has no interest that conflicts with the interests of the child s/he represents, and has the knowledge and skills that ensure adequate representation of the child.

An individual is not disqualified as an agency employee fr appointment as a surrogate solely because s/he is paid by th agency to serve as a surrogate parent.

The surrogate parent may represent the child in all matters relating to the identification, evaluation and educational placement of the child, and the provision of a free appropriate public education to the child.

### *Access to Records*

Your district must permit you to inspect and review any educational records relating to your child with respect to th identification, evaluation and educational placement of you child, and the free provision of a free appropriate public education to your child, which are collected, maintained, o used by the district under Part B of the Individuals with Disabilities Education Act.

The district must comply with a request without unnecessar delay and before any meeting regarding an individualized education program or hearing relating to the identification, evaluation and educational placement of your child, and in no case, more than 45 days after the request has been made.

- Your right to inspect and review educational records under this section includes:
- The right to a response form the participating agenc to reasonable requests for explanations and interpretations of the records.
- Your right to have your representative inspect and review the records.
- Your right to request that the agency provide copies the records containing information if failure to provi these copies would effectively prevent you from exercising your right to inspect and review the recor

The district may presume that you have authority to inspect and review records relating to your child unless the agency has been advised that you do not have the authority under applicable territorial law governing such matters as guardianship, seperation and divorce.

If any education record includes information on more than o child, you have the right to inspect and review only the information relating to your child or to be informed of the specific information.

The district must provide you, on request, a list of the types and locations of education records collected, maintained, or used by the agency.

### *Fees for Searching, Retrieving and Copying Records*

The district may not charge a fee to search for or to retrieve information under this part, but may charge a fee for copies of records which are made for parents under this part if the fee does not effectively prevent parents from exercising their right to inspect and review those records.

### *Record of Access*

The district must keep a record of parties obtaining access to educational records collected, maintained, or used under this part (except access by parents and authorized employees of the participating agency), including the name of the party, the date access was given, and the purpose for which the party is authorized to use the records.

### *Amendment of Records at Parent Request*

If you believe that information in educational records collected, maintained or used under this part is inaccurate or misleading or violates the privacy or other rights of your child, you may request that the agency that maintains the information amend the information.

The agency must decide whether to amend the information in accordance with your request within a reasonable period of time upon receipt of your request. If the agency decides to refuse to amend the information as per your request, it must inform you of the refusal and of your right to a hearing to challenge the information in your child's educational record to ensure that it is not inaccurate, misleading or otherwise in violation of the privacy or other rights of your child.

If, as a result of the hearing, the agency decides that the information is not inaccurate, misleading, or otherwise in violation of the privacy or other rights of your child, it must inform you of your right to place in the records it maintains on your child a statement commenting on the information or setting forth any reasons for disagreeing with the decision of the agency.

Any explanation placed in your child's records under this section must be maintained by the agency as part of the records of the child as long as the record or contested portion is maintained by the agency. If the records of the child or the contested portion is disclosed by the agency to any party, the explanation must also be disclosed to the party.

### *Definitions*

*Consent* means that you have been fully informed of all information relevant to the activity for which consent is sought, in your native language or other mode of communication.

- You understand and agree in writing to the carrying out of the activity for which your consent is sought, and the consent describes that activity and lists the records (if any) that will be released and to whom.
- You understand that the granting of consent is voluntary on your own and can be revoked at any time by informing the district in writing that you are revoking your consent.

*Evaluation* means procedures used in accordance with sections 300.530-300.634 of the Individuals with Disabilities Education Act to determine whether a child is handicapped and the nature and extent of the special education and related services that the child needs. The term means procedures used selectively with an individual child and does not include basic tests administered to, or procedures used with, all children in a school, grade or classroom.

*Independent educational evaluation* means an evaluation conducted by a qualified examiner who is not employed by the public agency responsible for the education of the child in question.

*Independent educational evaluation at public expense* means that the public agency either pays for the full cost of the evaluation or insures that the evaluation is otherwise provided at no cost to you.

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## To Get Answers . . . .

If you have questions or concerns about anything your child is doing at school, contact the right person!

Start with the classroom teacher. If you need additional assistance or information, contact the school principal.

The principal of your child's school is ________________________________

Phone Numbers: __________________________

Your child's school counselor is ________________________________

The CRT (Consulting Resource Teacher) at your school is: __________________________

Following is a record of the meetings, dates and signatures when PARENT RIGHTS have been given, explained and discussed.

| [illegible] | [illegible] | [illegible] | [illegible] |
|---|---|---|---|
| | IEP & Initial Placement Meeting | | |
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Guam Public School System
**Division of Special Education**

## Summary of Eligibility and Parent Notice: Eligibility Determination - SPF 3.3

Date: ___________

| Student | DOB | Grade | School |
|---|---|---|---|
| | | | |

**Dear Parents**: On ___________________ an Eligibility Meeting was conducted to determine whether or not your child meets eligibility requirements to receive special education.

The following evaluations, tests, reports, and/or records were used as a basis in making the eligibility determination:

- ☐ Psycho educational assessment report
- ☐ Medical records / Case History
- ☐ Teacher reports & work samples
- ☐ Achievement data
- ☐ Review of cumulative record
- ☐ Classroom observation
- ☐ Adaptive Behavior Scale
- ☐ Speech/Language Assessment Report
- ☐ Developmental Data

What language was used in the assessment/s of this student? ________________________________________

An interpreter was used during the pre-placement evaluation: _____ Yes _____ No

### Eligibility Determination

☐ The assessment data does not support the presence of a disability according to federal and local regulations, therefore the student IS NOT ELIGIBLE for special education services.

A representative from your child's school will be contacting you to:

☐ Discuss the test results and to identify alternatives to special education.
☐ A copy of Parent Rights in Identification, Evaluation and Placement is attached. Please read it carefully and if you have any questions, contact the Division of Special Education at 475-0546

☐ Based upon the assessment data detailed in the Summary of Evaluation and attached documents, the student is experiencing a disability according to federal and local regulations. The DISABILITY is ______________________________

☐ This student is also IN NEED OF SPECIAL EDUCATION services and therefore is eligible for special education services.
☐ This student is experiencing a disability, but does not need special education services, and therefore is not eligible for special education.
☐ I/we attended the Eligibility Meeting and received clear and satisfactory explanations about evaluation, eligibility and our options.

______________________________ Parent/s of Student

______________ Date

We are in unanimous agreement with this eligibility determination (Signature & Position):

| | |
|---|---|
| | Principal or Administrator |
| | Student's Teacher or Age/grade level Teacher |
| | CRT / Service Coordinator |
| | Psychologist |
| | Speech /Language Therapist |
| | Social Worker |
| | Nurse / School Health Counselor |

WHITE: Special Education • YELLOW: School • PINK: Parents

**Division of Special Education**
Guam Public School System

**Date:** ____________

## Parent Notice: Consent for Initial Placement in Special Education - SPF 4.2.5

| | | | |
|---|---|---|---|
| Name | DOB | Grade | School |

Dear Parents:

Your child has been evaluated and found eligible to receive special education services as described in your child's Individual Education Program (IEP) or Individual Family Services Plan (IFSP). In order to meet your child's unique needs, the IEP/IFSP committee has chosen the following placements for your child:

- ☐ All services within the natural environment with related and/or supplemental services.
- ☐ All instruction in a regular classroom program with related and/or supplemental services.
- ☐ Instruction in a regular classroom for a majority of the school day with part-time (less than or equal to 50% of the school day) special education services.
- ☐ Instruction/services from a special education program for the majority of the school day (more than 50% of the day).
- ☐ All instruction in a special education classroom/program on a regular school campus.
- ☐ Off-island placement.
- ☐ Other (specify): ____________________

The basis for the proposed placement is supported in the documents checked below:

- ☐ Summary of Evaluation
- ☐ IEP
- ☐ Eligibility Report
- ☐ Medical or Physician's Report
- ☐ IFSP
- ☐ Developmental Evaluation
- ☐ Learning Disability Report
- ☐ ____________
- ☐ ____________

Other factors relevant to this proposed action are: ____________________

____________________

Less restrictive placement options were considered and rejected for the following reasons: ____________

____________________

(Children ages 0-5 only): Parents declined services for the following reasons: ____________

____________________

An explanation of your rights regarding the identification, evaluation and placement of your child under federal and territorial law and regulations is attached for your review. Please call me at ____________ if you have any questions.

____________________
CRT or Service Coordinator

____________________
Principal

**Please return the original of this form to the Principal of the school or program Service Coordinator**

**Parent Consent:**

- ☐ I have received a copy of my child's: ☐ IEP ☐ IFSP and I understand the described services and recommended placement. I understand that my consent is voluntary and may be revoked at any time.
- ☐ I consent to the initial placement of my child as described in the IEP placement form.
- ☐ I do not consent to the initial placement of my child as described in the IEP placement form.

____________________
Signature of Parent or Guardian

____________
Date

WHITE: Special Education • YELLOW: School • PINK: Parents

Guam Department of Education
**Division of Special Education**
Infant & Toddler Early Intervention Program

## Individual Family Service Plan (IFSP) - SPF 4.2.4

| | | | | |
|---|---|---|---|---|
| Name *(last, first, middle initial)* | Sex | DOB | IFSP Date | |
| CRT | Ethnic | | Primary Language | ☐ Initial<br>☐ Review |
| Parents/Guardian | Home Phone | | Work Phone | Other |
| Home Address | Mailing Address | | | |

### Description of Early Intervention Services

| | | | |
|---|---|---|---|
| Services: | Frequency: | Intensity: | minutes |
| | Service Type: | ☐ Child w/ Caregiver | ☐ Group w/ Caregiver |
| | *Natural Environment in which services are provided:* | | |
| Services delivered by: | ☐ Home | ☐ Center | ☐ Other: |

| | | | |
|---|---|---|---|
| Services: | Frequency: | Intensity: | minutes |
| | Service Type: | ☐ Child w/ Caregiver | ☐ Group w/ Caregiver |
| | *Natural Environment in which services are provided:* | | |
| Services delivered by: | ☐ Home | ☐ Center | ☐ Other: |

| | | | |
|---|---|---|---|
| Services: | Frequency: | Intensity: | minutes |
| | Service Type: | ☐ Child w/ Caregiver | ☐ Group w/ Caregiver |
| | *Natural Environment in which services are provided:* | | |
| Services delivered by: | ☐ Home | ☐ Center | ☐ Other: |

Other services *(not required or covered by Part H)*:

Comments:

| | | | |
|---|---|---|---|
| Date of Last Assessment | Next Reassessment | IFSP Implementation<br>from to | Next Review Date |

I have participated in the development of this IFSP and the contents of the IFSP have been fully explained to me. I understand that I have the right to refuse services without jeopardizing my rights to other services.

☐ I have a copy of my Parent Rights and these have been explained to me.

Parent/Guardian Signature ______________________ Date: ____________

| | | |
|---|---|---|
| ***Signature/Position*** | Signatures of IFSP Committee | ***Signature/Position*** |

CRT

PRINCIPAL/Program Coordinator

PARENT

WHITE: Special Education YELLOW: Child's Folder PINK: Parents

# IFSP: Outcomes & Family Concerns, Priorities and Resources
## SPF 4.2.3 Child

| | | | |
|---|---|---|---|
| **Name (Last, First, Middle Initial)** | **D.O.B.** | **Service Coordinator / Position** | **Date** |

**Family Concern for Child Addressed: (Needs)**

**Outcome Area:**

**Person/s Responsible:**

**Present Level of Child's Functioning: (Strengths)**

| Outcomes | Intervention/ Strategies/ Materials | Timeline | | Review Date/ Comments |
|---|---|---|---|---|
| | | Initiation | Achieved | |
| | | | | |

WHITE: Special Education Office / YELLOW: Child's Individual Folder / PINK: Parent Copy

Guam Public School System
Division of Special Education

## Case Manager Notes - SPF 6.3.3

Date ____________

| Name | DOB | Grade | School |
|---|---|---|---|
| | | | |
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|---|---|
| **CRT's Signature:** | **Date:** |

WHITE: Special Education • YELLOW: School

# PEDS 3.1a Developmental Profile

e______________________________ Eval. Date____________ Age______

| Developmental Level in Months | Cognitive | Receptive Language | Expressive Language | Gross Motor | Fine Motor |
|---|---|---|---|---|---|
| 39-41 | ____ | ____ | ____ | ____ | ____ |
| 36-38 | ____ | ____ | ____ | ____ | ____ |
| 33-35 | ____ | ____ | ____ | ____ | ____ |
| 30-32 | ____ | ____ | ____ | ____ | ____ |
| 27-29 | ____ | ____ | ____ | ____ | ____ |
| 24-26 | ____ | ____ | ____ | ____ | ____ |
| 21-23 | ____ | ____ | ____ | ____ | ____ |
| 18-20 | ____ | ____ | ____ | ____ | ____ |
| 15-17 | ____ | ____ | ____ | ____ | ____ |
| 12-14 | ____ | ____ | ____ | ____ | ____ |
| 10-11 | ____ | ____ | ____ | ____ | ____ |
| 8-9 | ____ | ____ | ____ | ____ | ____ |
| 6-7 | ____ | ____ | ____ | ____ | ____ |
| 4-5 | ____ | ____ | ____ | ____ | ____ |
| 2-3 | ____ | ____ | ____ | ____ | ____ |
| 0-1 | ____ | ____ | ____ | ____ | ____ |

| | | | | | |
|---|---|---|---|---|---|
| Hearing: | WNL | Mild | Moderate | Severe | Profound |
| Vision: | WNL | Partial sighted | Legally blind | Light perception | Totally Blind |

/Emotional: Not Significant — Highly significant
1 - - - - - - - - - 2 - - - - - - - - - 3 - - - - - - - - - - 4 - - - - - - - - - 5

Adaptive: Age Appropriate — Severely delayed
1 - - - - - - - - - 2 - - - - - - - - - 3 - - - - - - - - - - 4 - - - - - - - - - 5

Speech: WNL — Impaired
1 - - - - - - - - - 2 - - - - - - - - - 3 - - - - - - - - - - 4 - - - - - - - - - 5

Health: WNL — Impaired
1 - - - - - - - - - 2 - - - - - - - - - 3 - - - - - - - - - - 4 - - - - - - - - - 5

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## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## PEDS 1.3a Case History Form (Newborn)

PEDS # ______ Child's Name ______________________________ DOB ______________

Interviewer ______________________________________ Date ______________

Parents ________________ / _____ / ________________ / _____ Phone # ____________
Father Age Mother Age

### I. PREGNANCY INFORMATION

1. At what time during your pregnancy did you realize that you were pregnant? Month ______________

2. In what month did you have your first prenatal visit? ______________

3. How much weight did you gain during your pregnancy? ______________

4. How many times have you been pregnant? _______

   Miscarriages _______ Abortions _______
   Still Births _______ Live Births _______

5. What advice were you given by family or friends about what to do or what not to do wile you were pregnant?

   Relationship of person giving advice: ________________ Age: ________

6. Did you take any special precautions while you were pregnant?

7. Prior to or during your pregnancy were you diagnosed as having a chronic disease? Yes ________ No ________
   (If a positive response to please circle category)

   A. Diabetes
   B. High Blood Pressure
   C. Alcoholism
   D. Drug Dependency
   E. Neurological Disease
   F. Cardiac Diseases
   G. Gastrointestinal Disease
   H. Respiratory Disease
   I. Skin Diseases
   J. Autoimmune Diseases
   K. Endocrine Diseases
   L. Cancers
   M. Psychiatric Diseases
   N. Other

8. If positive response to #7. Please list:
   a. age of onset of disease ____________
   b. Date of first diagnosis or treatment ____________
   c. Current treatment during pregnancy ____________

9. During your pregnancy did you have any acute illness.

10. If so, during what month of your pregnancy did this illness occur?__________

11. How long did you have signs or symptoms of the illness?____________

12. Did you see a physician____, nurse____, or traditional healer____ for treatment? (Describe diagnosis and treatment).

13. During your pregnancy were you subjected to any trauma such as:
car accidents? Yes___ No___
Blows to head Yes___ No___
Blows to abdomen Yes___ No___

If positive response to #13, state:
Treatment:____________________________________________________________
Hospitalized Yes___ No___

14. Did you receive x-rays during your pregnancy? Yes___ No___

What type__________________________________ How many times____________

15. Were you exposed to any harmful chemicals during your pregnancy (insecticides, pesticides, asbestos)?

16. During your pregnancy did you:

a. smoke cigarettes? Yes___ No___ How much?________ How long?________
b. drink alcohol? Yes___ No___ How much?________ How often?________
c. smoke marijuana? Yes___ No___ How much?________ How often?________
d. betel nut? Yes___ No____ How often?________
e. other drugs? Yes___ No___
f. caffeine type beverages? Yes___ No___ How much?____ How often?____
g. chewing tobacco? Yes___ No___ How often?__________

## II. BIRTH INFORMATION

1. How old were you when this child was born? ____________________

2. What type of delivery did you have? __SVD __IVD __C/S __XC/S __Forceps

3. In what position was your baby born? __vertex __breech
___other_______

4. How long was the labor? ____________(hours)

5. Were there any complications during the deliver? Please describe.

___Labor greater than 18 hrs. ___Toxemia
___Placenta Previa ___Birth trauma
___Abruptio placenta ___Other
___High blood pressure ___Cord compression

6. If there is a positive response to #5 then describe complications.

7. What did this baby weigh?_____________ How long was s/he?____________

8. Was the baby on time, early, or late? _____
Gestational Age at delivery?______________

9. What was your baby's Apgar score? ___ 1 min. ___ 5 min. ___ 10 min.

10. What was this baby's condition when s/he was first born?
(Describe as healthy, not breathing, blue, etc.)

11. Was the baby discharged from the hospital with you? Please explain.
(Describe as healthy, not breathing, blue, etc.)

12. If not, how long was the baby hospitalized?

## III. MEDICAL-HEALTH INFORMATION (Of this child)

1. Has your child ever experienced any of the following?

| Condition | Age | Treatment |
|---|---|---|
| ____High fever ____ | ____ | ____ |
| ____Convulsions ____ | ____ | ____ |
| ____Ear Infections ____ | ____ | ____ |
| ____Flu (Cold, cough, etc.) ____ | ____ | ____ |
| ____Dehydration ____ | ____ | ____ |
| ____Mumps ____ | ____ | ____ |
| ____Chicken pox ____ | ____ | ____ |
| ____Measles ____ | ____ | ____ |
| ____Whooping Cough ____ | ____ | ____ |
| ____Urine infection ____ | ____ | ____ |
| ____Anemia ____ | ____ | ____ |
| Other infections ____ (Specify) | ____ | ____ |
| Broken bones or sprains ____ (Specify) | ____ | ____ |
| Other accidents ____ (Specify) | ____ | ____ |
| Allergies ____ (Specify) | ____ | ____ |
| Hospitalizations ____ (Explain reason) | ____ | ____ |
| Other illnesses ____ (Specify) | ____ | ____ |

2. Is this child currently being treated for a continuing medical or health problem? Is s/he on any medications? (Please specify the problem and describe the treatment.)

3. Date of last visit to physician____

   Reason for visit____

4. Does your child have any nutritional or weight problems? If yes, please describe.

   Weight when last seen by health care provider/or when discharged from hospital____.

5. Type of feeding:

   ____Bottle
   ____Formula
   ____Breast
   ____Frequency of feedings

## IV. DEVELOPMENTAL ACHIEVEMENTS

1. General development: What age did your child first do the following:

______ Hold head erect and steady
______ Follow objects with eyes
______ Smile
______ Turn towards sounds

2. What is the primary language spoken in the home?
Is more than one language spoken in the home?

## V. CHILD CARE INFORMATION

1. Who takes care of this child most of the time? (yourself, grandmother, other relatives, baby sitter, etc.)

2. What advice have you been given by family or friends about taking care of the baby?

3. How does this child spend his/her time when s/he's awake? (Describe)

4. What is your primary concern about your baby at this time? (Please discuss)

5. In general, how easy/difficult is your child in general to take care of?

______ About average ______ Easier than most kids
______ More difficult than most kids

## IV. NEONATAL PERCEPTION INVENTORY

You have had a chance to live with your baby for ____ weeks now. Please check the blank you think best describes your baby.

| | A lot | More than average | Average amount | Very little | None |
|---|---|---|---|---|---|
| How much crying has your baby done? | ___ | ___ | ___ | ___ | ___ |
| How much trouble has your baby had feeding? | ___ | ___ | ___ | ___ | ___ |
| How much spitting up or vomiting has your baby done? | ___ | ___ | ___ | ___ | ___ |
| How much trouble has your baby had in sleeping? | ___ | ___ | ___ | ___ | ___ |
| How much difficulty has your baby had with bowel movements? | ___ | ___ | ___ | ___ | ___ |
| How much difficulty has your baby had in settling down to a predictable pattern of eating and sleeping? | ___ | ___ | ___ | ___ | ___ |
| Values | 5 | 4 | 3 | 2 | 1 |

Adapted from Broussard, E., and Hartner, M.S.: Further consideration regarding maternal perception of the first born. In Hellmuth, J., editor: Exceptional infant, vol 2, New York, 1971, Brunner/Mazel, Inc., pp. 444-445.

COMMENTS:

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# FAMILY NEEDS SURVEY

*Donald Bailey*
*Rune Simeonsson*
*Frank Porter Graham*
*Child Development Center*
*The University of North Carolina*
*at Chapel Hill*
*@ All Rights Reserved 1985*

*FORM H*

---

Family Name/ID__________________ Relationship to child______________

Date_______________

---

INSTRUCTIONS: Listed below are some of the needs expressed by parents of special children. Please read each statement and decide if you need help in this area. Then circle the number (1, 2 or 3) which represents your response to the need.

| NEEDS FOR INFORMATION | Definitely do not need help with this | Not sure | Definitely need help with this |
|---|---|---|---|
| 1. I need more information about my child's condition or disability | 1 | 2 | 3 |
| 2. I need more information about how to handle my child's behavior | 1 | 2 | 3 |
| 3. I need more information on how to teach my child | 1 | 2 | 3 |
| 4. I need more information on how to play with or talk to my child | 1 | 2 | 3 |
| 5. I need more information about the services that my child might receive in the future | 1 | 2 | 3 |
| 6. I need more information on the services that are presently available for my child | 1 | 2 | 3 |

| | Definitely do not need help with this | Not sure | Definitely need help with this |
|---|---|---|---|
| 7. I need more information about how children grow and develop | 1 | 2 | 3 |
| NEEDS FOR SUPPORT | | | |
| 1. I need to have someone in my family that I can talk to more about problems | 1 | 2 | 3 |
| 2. I need to have more friends that I can talk to | 1 | 2 | 3 |
| 3. I need to have more opportunities to meet and talk with parents of handicapped children | 1 | 2 | 3 |
| 4. I need to have more time just to talk with my child's teacher or therapist | 1 | 2 | 3 |
| 5. I would like to meet more regularly with a counselor (psychologist, social worker, psychiatrist) to talk about problems | 1 | 2 | 3 |
| 6. I need to talk more to a minister who could help me deal with problems | 1 | 2 | 3 |
| 7. I need reading material about other parents who have a child similar to mine | 1 | 2 | 3 |
| 8. I need to have more time for myself | 1 | 2 | 3 |
| EXPLAINING TO OTHERS | | | |
| 1. I need more help in explaining my child's condition to either my parents or my spouse's parents | 1 | 2 | 3 |
| 2. My spouse needs help in understanding and accepting our child's condition | 1 | 2 | 3 |
| 3. I need more help in how to explain my child's condition to his/her siblings | 1 | 2 | 3 |
| 4. I need help in knowing how to respond when friends. neighbors, or strangers ask questions about my child's condition | 1 | 2 | 3 |

|  | Definite do not need help with this | Not sure | Definitely need help with this |
|---|---|---|---|
| 5. I need help in explaining my child's condition to other children | 1 | 2 | 3 |
| **COMMUNITY SERVICES** |  |  |  |
| 1. I need help locating a doctor who understands me and my child's needs | 1 | 2 | 3 |
| 2. I need help locating a dentist who will see my child | 1 | 2 | 3 |
| 3. I need help locating babysitters or respite care providers who are willing and able to care for my child | 1 | 2 | 3 |
| 4. I need help in locating a day care center or preschool for my child | 1 | 2 | 3 |
| 5. I need help in getting appropriate care for my child in our church or synagogue nursery during services | 1 | 2 | 3 |
| **FINANCIAL NEEDS** |  |  |  |
| 1. I need more help in paying for expenses such as food, housing, medical care, clothing, or transportation | 1 | 2 | 3 |
| 2. I need more help in getting special equipment for my child's needs | 1 | 2 | 3 |
| 3. I need more help in paying for therapy, day care, or other services that my child needs | 1 | 2 | 3 |
| 4. I or my spouse need more counseling or help in getting a job | 1 | 2 | 3 |
| 5. I need more help paying for babysitting or respite care | 1 | 2 | 3 |

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| | Definitely do not need help with this | Not sure | Definitely need help with this |
|---|---|---|---|
| 6. I need more help paying for toys that my child needs | 1 | 2 | 3 |

FAMILY FUNCTIONING

| | | | |
|---|---|---|---|
| 1. Our family needs help in discussing problems and reaching solutions | 1 | 2 | 3 |
| 2. Our family needs help in learning how to support each other during difficult times | 1 | 2 | 3 |
| 3. Our family needs help in deciding who will do household chores, child care, and other family tasks | 1 | 2 | 3 |
| 4. Our family needs help in deciding on and doing recreational activities | 1 | 2 | 3 |

WHAT ARE YOUR GREATEST FAMILY NEEDS AT THIS TIME? THESE MAY INCLUDE NEEDS LISTED ON THE SURVEY OR OTHER NEEDS YOU MAY HAVE.

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[illegible] Inventory for [illegible]
ttye M. Caldwell and Robert H. Br[illegible]

Family Name______________________ Date__________ Visitor______________

Child's Name______________________ Birthdate__________ Age______ Sex______

Caregiver for visit______________________ Relationship to child______________

Family composition________________________________________________
(Persons living in household, including sex and age of children)

Family Ethnicity______________ Language Spoken______________ Maternal Education__________ Paternal Education______

Is Mother employed?______ Type of work when employed______________ Is Father employed?______ Type of Work when employed______________

Address______________________________________ Phone______________

Current child care arrangements________________________________________

Summarize past year's arrangements______________________________________

Caregiver for visit______________________ Other persons present______________

## SUMMARY

| | Subscale | Score | Lowest Middle | Middle Half | Upper Fourth |
|---|---|---|---|---|---|
| I. | Emotional and Verbal RESPONSIVITY of Parent | | 0-6 | 7-9 | 10-11 |
| II. | ACCEPTANCE of Child's Behavior | | 0-4 | 5-6 | 7-8 |
| III. | ORGANIZATION of Physical and Temporal Environment | | 0-3 | 4-5 | 6 |
| IV. | Provision of Appropriate PLAY MATERIALS | | 0-4 | 5-7 | 8-9 |
| V. | Parent INVOLVEMENT with Child | | 0-2 | 3-4 | 5-6 |
| VI. | Opportunities for VARIETY in Daily Stimulation | | 0-1 | 2-3 | 4-5 |
| | TOTAL SCORE | | 0-25 | 26-36 | 37-45 |

For rapid profiling of a family, place an X in the box that corresponds to the raw score on each subscale and the total score.

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Place a plus (+) or minus (-) in the … alongside each item if the behavior is obse… reports that the conditions or events … characteristic of the home environment. … subtotal and the total on the front side of the Record Sheet.

### I. Emotional and Verbal RESPONSIVITY

| | |
|---|---|
| 1. Parent spontaneously vocalized to child twice. | |
| 2. Parent responds verbally to child's verbalizations. | |
| 3. Parent tells child name of object or person during visit. | |
| 4. Parent's speech is distinct and audible. | |
| 5. Parent initiates verbal exchanges with visitor. | |
| 6. Parent converses freely and easily. | |
| 7. Parent permits child to engage in "messy" play. | |
| 8. Parent spontaneously praises child at least twice. | |
| 9. Parent's voice conveys positive feelings toward child. | |
| 10. Parent carresses or kisses child at least once. | |
| 11. Parent responds positively to praise of child offered by visitor. | |
| Subtotal | |

### II. ACCEPTANCE of Child's Behavior

| | |
|---|---|
| 12. Parent does not shout at child. | |
| 13. Parent does not express annoyance with or hostility to child. | |
| 14. Parent neither slaps nor spanks child during visit. | |
| 15. No more than one instance of physical punishment during past week. | |
| 16. Parent does not scold or criticize child during visit. | |
| 17. Parent does not interfere or restrict child more than 3 times. | |
| 18. At least ten books are present and visible. | |
| 19. Family has a pet. | |
| Subtotal | |

### III. ORGANIZATION of Environment

| | |
|---|---|
| 20. Substitute care is provided by one of 3 regular substitutes. | |
| 21. Child is taken to grocery store at least once a week. | |
| 22. Child gets out of house at least 4 times a week. | |
| 23. Child is taken regularly to doctor's office or clinic. | |
| 24. Chidl has a special place for toys and treasures. | |
| 25. Child's play environment is safe. | |
| Subtotal | |

### IV. Provision of PLAY MATERIALS

| | |
|---|---|
| 26. Muscle activity toys or equipment. | |
| 27. Push or pull toy. | |
| 28. Stroller or walker, kiddie car, scooter or tricycle. | |
| 29. Parent provides toys for child during visit. | |
| 30. Learning equipment appropriate to age-cuddly toys or role-playing toys. | |
| 31. Learning facilitators--mobile, table and chairs, high chair, play pen. | |
| 32. Simple eye-hand coordination toys. | |
| 33. Complex eye-hand coordination toys (those permitting combination) | |
| 34. Toys for literature and music. | |
| Subtotal | |

### V. Parental INVOLVEMENT with Child

| | |
|---|---|
| 35. Parent keeps child in visual range, looks at often. | |
| 36. Parent talks to child while doing household work. | |
| 37. Parent consciously encourages developmental advance. | |
| 38. Parent invests maturing toys with value via personal attention. | |
| 39. Parent structures child's play periods. | |
| 40. Parent provides toys that challenge child to develop new skills. | |
| Subtotal | |

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## VI. Opportunities

| | |
|---|---|
| 41. Father provides some care [illegible]y. | |
| 42. Parent reads stories to child at least 3 times weekly. | |
| 43. Child eats at least one meal per day with mother and father. | |
| 44. Family visits relatives or receives visits once a month or so. | |
| 45. Child has three or more books of his/her own. | |
| Subtotal | |

| | |
|---|---|
| TOTAL SCORE | |

*For complete wording of items, please refer to the Administration Manual.

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# Family Support Scale

Carl J. Dunst, Vicki Jenkins, & Carol M. Trivette

Name:______________________________________ Date:____________________

Listed below are people and groups that often times are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family.

Please **circle** the response that best describes how helpful the sources have been to your family during the past **3 to 6 months**. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

| How helpful has each of the following been to you in terms of raising your child(ren): | Not Available | Not at All Helpful | Sometimes Helpful | Generally Helpful | Very Helpful | Extremely Helpful |
|---|---|---|---|---|---|---|
| 1. My parents | NA | 1 | 2 | 3 | 4 | 5 |
| 2. My spouse or partner's parents | NA | 1 | 2 | 3 | 4 | 5 |
| 3. My relatives/kin | NA | 1 | 2 | 3 | 4 | 5 |
| 4. My spouse or partner's relatives'kin | NA | 1 | 2 | 3 | 4 | 5 |
| 5. Spouse or partner | NA | 1 | 2 | 3 | 4 | 5 |
| 6. My friends | NA | 1 | 2 | 3 | 4 | 5 |
| 7. My spouse or partner's friends | NA | 1 | 2 | 3 | 4 | 5 |
| 8. My own children | NA | 1 | 2 | 3 | 4 | 5 |
| 9. Other parents | NA | 1 | 2 | 3 | 4 | 5 |
| 10. Co-workers | NA | 1 | 2 | 3 | 4 | 5 |
| 11. Parent groups | NA | 1 | 2 | 3 | 4 | 5 |
| 12. Social groups/clubs | NA | 1 | 2 | 3 | 4 | 5 |
| 13. Church members/minister | NA | 1 | 2 | 3 | 4 | 5 |
| 14. My family or child's physician | NA | 1 | 2 | 3 | 4 | 5 |
| 15. Early childhood Intervention program | NA | 1 | 2 | 3 | 4 | 5 |
| 16. School/day-care center | NA | 1 | 2 | 3 | 4 | 5 |
| 17. Professional helpers (social workers, therapists, teachers, etc.) | NA | 1 | 2 | 3 | 4 | 5 |
| 18. Professional agencies (public health, social services, mental health, etc.) | NA | 1 | 2 | 3 | 4 | 5 |
| 19.____________________ | NA | 1 | 2 | 3 | 4 | 5 |
| 20.____________________ | NA | 1 | 2 | 3 | 4 | 5 |

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books. May be reproduced.

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## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVIC

## PEDS 5.4 Agreement to Participate in Follow-Up Program for High-Risk Infants

COE, Dean's Circle #17
UOG Station
Mangilao, GU 96923
(671)734-2577

Infants born prematurely or with neonatal complications often confront unique circumstances as they grow and develop. Guam Memorial Hospital (GMH) and the Pediatric Evaluation and Developmental Services (PEDS) are co-sponsoring a developmental Follow-Up Program for special care infants. We are seeking your permission to monitor your child's growth and development by including him/her in the GMH/PEDS Follow-Up Program.

The procedures are simple and entirely safe. They include the following: 1) Developmental evaluation and hearing test before charge from GMH; 2) A follow-up home visit two to four weeks post discharge; 3) Follow-up appointments at the PEDS for hearing, health and developmental evaluations when your baby is 3-4, 8-9 months, 15 months, 2 years, and yearly after that until the child is five years of age.

After each evaluation you will be given suggestions for developmentally appropriate activities for you to do with your child that are designed to facilitate your child's development. We will be happy to answer any questions you may have, prior to, during or after each evaluation. You will be informed of the results of each developmental evaluation. We will need to look at your child's hospital records to determine your child's condition at birth, treatment received, and selected background information. Your responses to the questionnaires, interview, and test results will be kept strictly confidential. There are no risks to your or your child. There is no charge for this service.

* * * * * *

**The GMH/PEDS Follow-Up Program has been fully explained to me.**

I certify that I have read and understand the foregoing, that I have been given satisfactory answers to my inquiries concerning project procedures and other matters and that I have been advised that I am free to withdraw my consent and to discontinue participation in the project or activity at any time without prejudice.

I herewith give my consent to participate (or, I consent to the participation of my minor child, or minor ward) in this project with the understanding that such consent does not waive any legal right nor does it release the principal investigator or the institution or any employee or agent thereof from liability for negligence or for any wrongful act or conduct.

Signature____________________________ Date____________________
Parent/Guardian

I hereby authorize the Pediatric Evaluation and Developmental Services to have access to my child's medical records at Guam Memorial Hospital.

Signature____________________________ Date____________________
Parent/Guardian

Signature____________________________ Date____________________
Witness

If you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in this study, contact: Office of Graduate School and Research, University of Guam, UOG Station, Mangilao, Guam 96923. Phone: 734-3676 or your local Mayor's office.

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| Appt. Date | Time | S/NS | Appt. Date | Time | S/NS | Appt. Date | Time | S/NS | Appt. Date | Time | S/NS |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | |
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THER INFORMATION:

| Date | Comments |
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# NEWBORN
# DEVELOPMENTAL SCREENING
# SCALE (NBDS)

by:

**W. June Holstrum, Ph.D.**
**University of Guam**
**Pediatric Evaluation and Developmental Services**

AME________________________ HOSP. #__________ ID #_______

OB____________ GA________ APGARS ____/____/____

OE____________ CHRON. AGE__________ ADJ. AGE________

ARENTS___________________________ PHONE________________

DDRESS____________________________________________________

**********************************************************************

| | Normal | Questionable | Abnormal |
|---|---|---|---|
| abituation | 1---------- | -----------2----------- | ----------3 |
| tten/Interact. | 4--5--6--7- | 8--9--10-11-12-13-14-15-16 | 17-18-19-20 |
| otor | 4--5--6--7- | 8--9--10-11-12-13-14-15-16 | 17-18-19-20 |
| b. Movements | 1---------- | 2----------3-----------4 | ----------5 |
| hysiological | 2-----3---- | 4-----5-----6-----7-----8 | ----9-----10 |
| eflexes | 1 = WNL | 2 = Questionnable | 3 = Abnormal |

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by W. June Holstrum. Ph..
University of Guam

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## PEDS 5.1 Intake Form (NICU)

Child's Name________________________ PEDS #__________ Date__________

Date of Birth__________________ Age______ Sex [ ] Male [ ] Female

Physician:____________________________________________

FAMILY INFORMATION:

Mother__________________________ Age________ Work Phone #__________

Occupation______________________________________________________

Father__________________________ Age________ Work Phone #__________

Occupation______________________________________________________

ome Address______________________________ Village__________________

ailing Address___________________________________________________

ome Phone #__________________

nsurance:__________________

### ETHNICITY

_____Child _____Mother _____Father

(01) Chamorro
(02) Filipino
(03) Micronesian Mix
(04) Northern Marianas
(05) Other Pacific Islander
(06) Chinese
(07) Japanese
(08) Korean
(09) Vietnamese
(10) Other Asian
(11) American Indian
(12) Afro-American
(13) Hispanic
(14) Caucasian
(15) Other
(16) Mix
(17) Palauan
(18) Trukese
(19) Kosraen
(20) Ponapean
(21) Marshallese
(22) Yapese

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## PEDS 5.2 Risk Register

Subj.#._____ Name:_______________________ HOSP.#_____________ D.O.B.______

GA (LMP)________ GA (ASSES)________ SEX_____ RACE_________________ GMH NR

APGARS: 1___ 5___ 10___ B.W.____G/____# LENGTH__cc/____"H.C.___cc/___

PLURALITY:___Singleton___Twin___Triplet___>3 DELIVERY: SVD IVD C/S XC/S

PRESENTATION: ___Vertex ___Breech ___Other DAYS ON RESPIRATOR:____________

Mother's Age:____

### Parental/Family Conditions

___ Maternal age <18 >35
___ Maternal PKU
Mother HIV positive
[illegible] of anticonvulsant,
[illegible]oplastic or anticoagulant drugs
___ Parental blindness
___ Parental substance abuse
___ Parental mental retardation
___ Parental mental illness
___ Difficulty in parental/infant bonding
___ Difficulty in providing basic parenting
___ Lack of stable housing
*___ Family history of childhood deafness
___ No prenatal care

TOTAL P/F CONDITIONS______________

* ABR Screening if one or more

### Neonatal Complications

*___ <1000 gms
*___ <1500 gms
___ <2000 gms
___ Resuscitation at birth
*___ Mechanical ventilation >6 hours
*___ Required oxygen >7 days
___ SGA <10%; LGA <90%
___ Head Circumference <10% >90%
*___ 5 min. Apgar less than 6
___ Hypoglycemia: <40 mg% >38 wks
<30 mg% <38 wks
___ Hypocalcemia: <7.5 mg
*___ Hyperbilirubinemia: >20
___ Seizures
*___ Suspected hearing impairment
___ Suspected vision impairment
___ Meconium Aspiration
___ Infant of diabetic

___ Suspected IVH
___ Extreme hypo/hypertonia
___ Hydrocephalus
___ Exchange Transfusion
___ Congenital Anomalies_____
*___ Chromosomal Defect
___ Cardiac Disorder/Anomalies
__________________
*___ Neonatal Infection
___ Feeding Problem
___ Persistent lethargy >72 ho
___ Multiple apneic episodes
*___ Cranio-facial anomalies
*___ Ototoxic medications >5 da

TOTAL NEONATAL COMPLICATIONS_____

PEDS Contact __ 1 = Yes 2 =

Results of NDSS:

_____ Habituation
_____ Attention/Interaction
_____ Motor
_____ Physiological Systems
_____ Abnormal Movements
_____ Reflexes

____________________________
Primary Care Physician

____________________________
Clinic

Discharge Date:_______________

Age at discharge__________days

TOTAL DEVEL. SCORE________

Comments/Concerns

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## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICE

### PEDS 2.4-A PERMISSION FOR EVALUATION
### AND
### RELEASE OF INFORMATION

I hereby give my full consent for the evaluation of my child ______________________________, by the staff of Pediatric Evaluation and Developmental Services (PEDS). I understand that any of the following procedures may be used to determine the eligibility status of my child for Special Education and Related Services.

- Speech/Language Evaluation
- Audiological Exam
- Case History
- Survey of Family Concerns, Priorities, Resources
- Health Screening
- Developmental or Psycho-Educational Evaluation
- Physical Therapy / Occupational Therapy
- Vision Screening

I also hereby authorize Pediatric Evaluation and Developmental Services (PEDS) to release this information to my child's physician, clinic, school or agency of the Government of Guam for the purpose of planning an appropriate education program for my child. I understand that all information collected during this evaluation will be kept confidential and will be used only by authorized personnel for the above stated purpose.

Signed: ______________________________

Relationship: ______________________________

Date: ______________________________

Witness: ______________________________

Child's Birthday: ____________________

# *Understanding My Signals*

## Help for Parents of Premature Infants

Brenda Hussey, M.A., MPH

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Special acknowledgements go to the nurses of the Intermediate Care Nursery, and to the parents for allowing me to work with their babies.

Dear Parent:

Although I have come early, and my body is small, I am ready and able to communicate. I have a special set of signals that can tell you when I am happy and not happy.

When I **am happy,** I like things just the way they are and I am ready to be held, fed, or played with. When **I am not happy and something is not right, I need a change**. At times I will do things to **make myself happy**. At other times, I will need your help. I may need to be fed or I may need my diaper changed. It may also be that I am too excited and need a rest.

I thought that a booklet with pictures would be most helpful to you. *Included are signals that may say:* **(1) I am happy and ready; (2) I am helping myself; and (3) I am not happy and need a change**. Please keep in mind that I am unique and that I have my own personal set of signals. It may be that I don't use all of the signals in this booklet. This is alright. You will just need to take some time to watch me and learn about me.

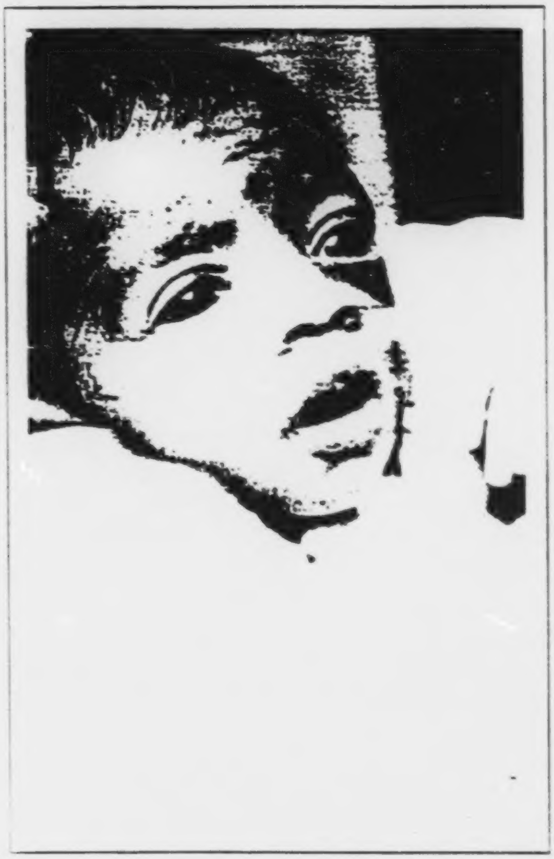
Also included are ways that you can help me by changing sights, sounds, and touches to make me happy. These are presented on pages 12 to 15 under "Changes that may Help me". Once again, keep in mind that I am unique and that these changes may or may not work, and that other changes may also be needed. There may be times when nothing will work. Please don't give up – try again later. When you do learn something neat about me (for example, I stop "spreading my fingers" when I have something to hold on to), write it down on the last page of this booklet as a reminder.

I hope that this booklet will help you get to know me better, and will teach you ways to respond to my signals. If you have any questions about this booklet or my signals, please ask my nurse, therapist, or teacher.

Love,

**Your New Baby**

# SIGNALS THAT MAY SAY
## *"I am happy and ready"*



I am alert and I coo.

My face, arms, and legs are relaxed.

©1988 Hussey

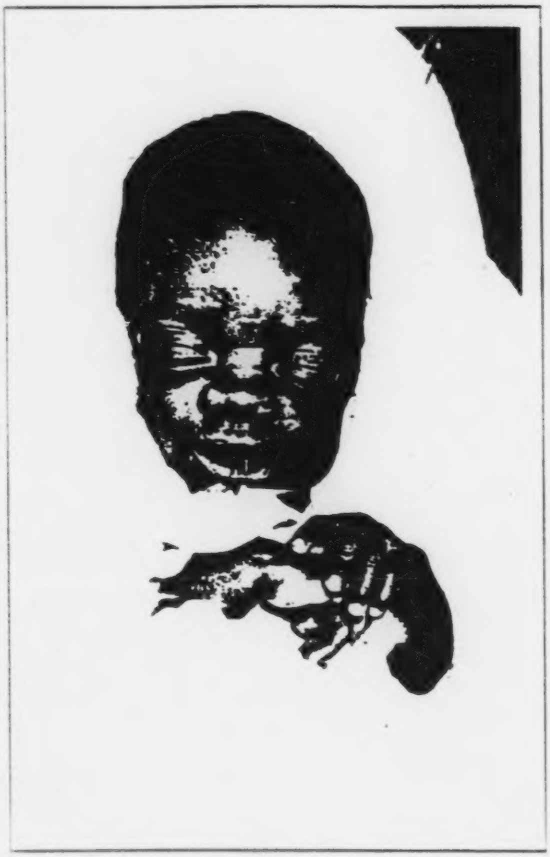
## SIGNALS THAT MAY SAY
## *"I am happy and ready"*

**I look at objects or people.**

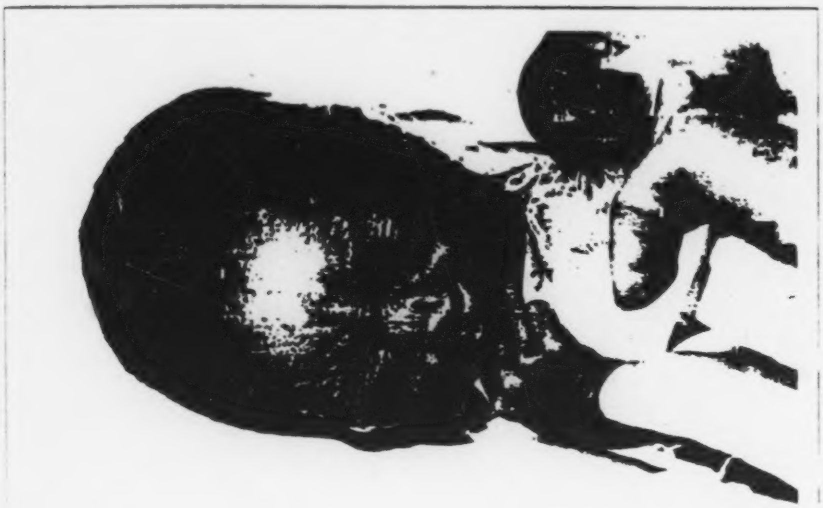
**My eyes are open and I try to smile.**

1988 Hussey

# SIGNALS THAT MAY SAY
## *"I am helping myself"*



I clasp my hands together–this prevents them from waving around.



I suck on my fingers or hand–this soothes me. If I have trouble getting my hand to my mouth, you may want to help me.

©1988 Hussey

## SIGNALS THAT MAY SAY

## *"I am not happy and need a change"*

**I salute.**

**I spread my fingers apart.**

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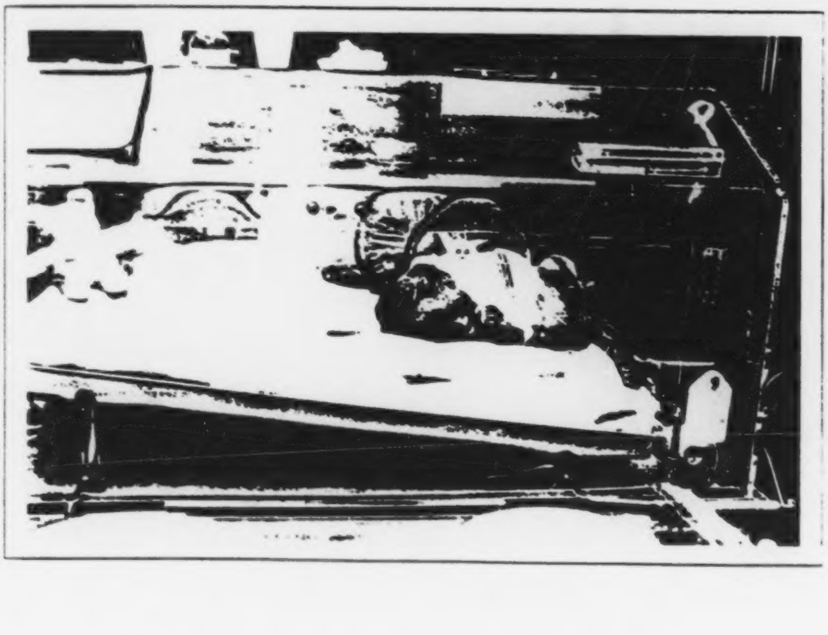
## SIGNALS THAT MAY SAY
## *"I am helping myself"*

**I go into a light sleep–this allows me to shut out sights and sounds.**



**I snuggle into corners of the bed–this makes me feel secure. Please check to see that I am breathing o.k. and that my head is *not* caught in anything.**

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## SIGNALS THAT MAY SAY
## *"I am not happy and need a change"*

I frown.

I grimace or grunt.

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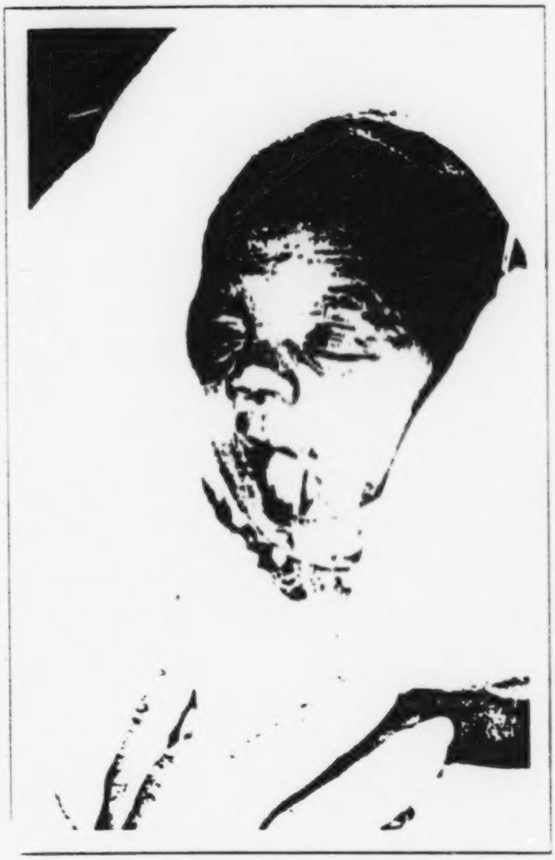
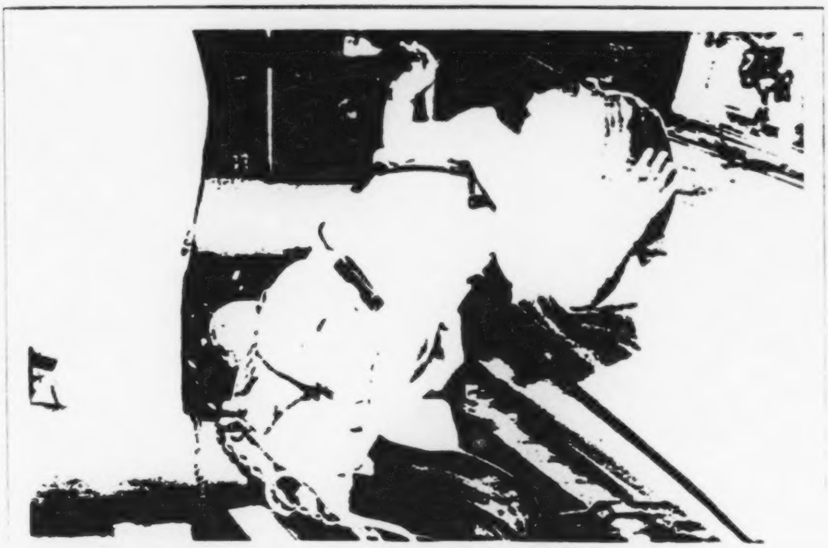
## SIGNALS THAT MAY SAY

## *"I am not happy and need a change"*



I yawn, sneeze, or hiccough.



I arch my back and neck, and push away.

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# SIGNALS THAT MAY SAY
## *"I am not happy and need a change"*

I look away.

I cry.

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# CHANGES THAT MAY HELP ME

Your touch can startle me. Try talking to me before you touch me. This will let me know that you are there.

Before playing with or feeding me, try laying me quietly on your lap. This doesn't have to be a nap. It's just a short break so that I don't get too excited.

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# CHANGES THAT MAY HELP ME

**While playing with me, talk softly and hold me about ten inches from your face–I will be able to see you better.**

**Bright lights may bother me. If my eyes are shut, try shading my eyes from the glare with your hand.**

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## CHANGES THAT MAY HELP ME

Provide me with a quiet time when I give a "not happy" signal. Try holding me quietly and firmly. This will give me a secure feeling.

When I am ready to interact, begin slowly with either a calm face, soft voice, or gentle touch. If this is still too much, let me grab your finger. Hold me quietly until I am ready.

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## CHANGES THAT MAY HELP ME

If I am still not happy, try tucking my arms in close to my chest or firmly wrapping me in a blanket.

When you are ready to lay me down, put me on my side or stomach. This is comfortable and safe.

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Henig, R. & Fletcher, A. (1983). *Your Premature Baby: The Complete Guide to Premie Care During that Crucial First Year.* New York: Ballantine Books.

Nance, S. (1984). *Premature Babies: A Handbook for Parents by Parents.* New York: Berkeley Books.

Parent Care, Inc., University of Utah Health Sciences, Room 2A 210, 50 North Medical Drive,
Salt Lake City, Utah 84132

My signals are:

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## POLICY AND PROCEDURE MANUAL

HANDBOOK FOR THE

DELIVERY OF SERVICES

1990-91

University of Guam, College of Education
Department of Education, Division of Special Education
Department of Public Health and Social Services

Ph. 734-2577

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES
# POLICY AND PROCEDURE MANUAL

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## 1.0 GENERAL INFORMATION

### 1.1 Description and Purpose:

Pediatric Evaluation and Developmental Services (PEDS) is a program jointly operated by the Guam Department of Education, Division of Special Education, the University of Guam College of Education, and the Department of Public Health and Social Services for the purpose of comprehensive diagnostic and referral services for children between birth and five years of age inclusive.

Pediatric Evaluation and Developmental Services (PEDS) is located in Dean's Circle, House #17 on the University of Guam campus. The primary purpose of the Center is to provide identification, screening, diagnosis, monitoring, and referral services for special needs infants and young children or those who are at-risk for developmental delays and related handicapping conditions.

The PEDS will also serve as a site for training and research. Students from Education, Nursing, Psychology, Social Work or other related fields may observe the Center's activities and gain practical experience through practicums or internships. Internships will also be available for students from other universities. Local and regional opportunities will be provided for students and professionals to engage in research related to young and special children.

The purpose of the screening and assessment components of PEDS is to identify special needs infants, young children, and their families at the earliest age possible in order to:

-to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay,

-to reduce the educational cost to our schools, by minimizing the need for special education and related services after handicapped infants and toddlers reach school age,

-to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society, and

-to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps.

The training component of the PEDS is designed to enhance the ability and effectiveness of professionals and future professionals to work with these young children and their families.
It is expected that through carefully designed research we may gain information that will allow assessment and early intervention programs:

-to be more aware of ethnic, cultural, and individual diversities,

-to enhance our capacity to provide quality early intervention programs, and

-to expand and improve existing early identification and intervention services.

### 1.2 Philosophy:

Children who are handicapped or at risk for handicapping conditions may need services at an early age in order to benefit from later opportunities in school. The Education of the Handicapped Act (EHA) insured that these rights to a free and appropriate public education were guaranteed for handicapped children ages 3-21. The Amendment to EHA, Public Law 99-457 provides an impetus and legal right to education and services for handicapped and at-risk infants and children from birth to age 3.

Guam is committed to providing services to handicapped infants and children at the earliest opportunity. The Pediatric Evalaution and Developmental Services (PEDS) Center is grounded in theories of infant and child development and in research in developmental, educational, psychological, and medical research. The Center is committed to providing a continuum of services through the use of a multi-disciplinary team of parents and professionals.

Infants and young children are uniquely dependent on their families for their survival and nurturance. This dependence necessitates a family-centered approach to early intervention. Each family has its own structure, roles, values, beliefs, and coping styles. Respect for and acceptance of this diversity is a cornerstone of family-centered early intervention. Early intervention systems and strategies must also reflect a respect for the racial, ethnic, and cultural diversity of families. Respect for family autonomy, independence, and decision making means that families must be able to choose the level and nature of early intervention's involvement in their life.

Family/professional collaboration and partnerships are the keys to family-centered early intervention. A collaborative approach does not mean, however, that families and professionals have equal authority in decision making. Respect for family autonomy and for the primacy of family beliefs and values dictates that, except in those rare instance that involve child abuse or neglect as defined by federal and local statutes, families have the final decision in all matters regarding their children. In a truly collaborative approach to intervention services, the right of families to make decisions for their children and themselves exists in harmony with the responsibility of professionals to share their knowledge, expertise, and concerns with families who seek early intervention services.

### 1.3 Staff:

PEDS will utilize a multi-disciplinary staff of professionals who specialize in working with young and special children. If the needs of a child or family require the expertise of a particular discipline that is not represented at PEDS Center, the case manager will refer the family to the agency or specialist needed.

## 2.0 PROCEDURES:

### 2.1 First Point of Contact:

Referrals to the Pediatric Developmental Services Center may come from a number of sources, such as Department of Education, Head Start, physicians, and clinics. Any pertinent medical and family information should accompany the referral. Families may also refer themselves. From the time of first contact between a family and PEDS, a family-centered approach will emphasize the family's preferences and priorities.

### 2.2 Intake and Evaluation Process:

Within three working days of initial referral to PEDS, contact will be made with the parents to set up an appointment at the PEDS Center. The first visit to PEDS will usually include:

-completion of the intake form (PEDS 1.1)
-signing of the consent for screening (PEDS 1.2)
-audiological exam (in some cases, such as when the child is referred by a physician for a follow-up of an ear infection, the audiological report may be all that is necessary)
-a case history (PEDS 1.3)
-a developmental screening for the child
-a health screening which will include height, weight, and HC measurements

Within 10 days of Intake, the case will be presented at the Case Review Meeting. This will be an in-house meeting attended by the PEDS staff. Based on family concerns, referral information, case history, health and developmental screening information, and audiological test results the team will decide if other evaluations need to be completed or other information needs to be collected. It may be determined that: a) the child/family does not need services at this time, b) the child's progress sould be monitored, c) a more in-depth evaluation is indicated.

#### 2.2.1 Child/family does not need services:

Without further evaluations, the child and family do not need early intervention services or further evaluations. In such instances, family members should be referred or linked to other resources that can help them with whatever concerns prompted the initial referral. A written report will be given to the family and the referral source containing screening results and recommendations.

#### 2.2.2 A Periodic rescreening/monitoring is recommended:

A child and family may not need intervention services at the time of initial contact, but concerns about future development may indicate a need for periodic rescreening. If the child's development is questionable, if the family or professionals are concerned about development and request rescreening, or if there is high risk for developmental delay, then the child will be scheduled for periodic screening. If at any of the rescreenings development appears to be delayed, a referral will be made for a more in-depth evaluation. At each screening the family will be given suggestions and ideas for activities, exercises, and games to facilitate development. Families may be referred or linked to other resources that can help them with other concerns.

2.2.3 **More in-depth evaluation is recommended:** When screening indicates the child/family is in need of more in-depth evaluation.

-Parent's Right (SPF 2.4) will be signed by the parents;
-The Permission for Evaluation Form (PEDS 2.4) will be signed by the parents;
-The Referral for Services Form (SPF 2.5) will be completed and sent to DOE.

An evaluation will be planned that will address family priorities and concerns. It will be determined what other evaluations need to be administered, what other information needs to be collected, and the time line in which these should be accomplished. If information from other agencies is needed, a Release of Information (SPF 1.1.2c) will be signed. The above forms may be signed at the end of the screening or when the famly returns to PEDS for the evaluation.

The in-depth evaluation will be completed within 30 calendar days of the case review meeting. It will be completed with as few tools as possible, with as few multi-disciplinary professionals as are needed to arrive at an accurate developmental evaluation, in a process which provides the family with a choice of options for time, and with sensitivity to the demand placed on the family. For 0-3 year old children, a representative from Guma Nene will assist in the evaluation.

For 0-3 year olds (as stated in P.L. 99-456, Sec. 677c): "With the parent's consent, early intervention services may commence prior to the completion" of the child's evaluation. This provision makes it possible for early intervention services to be provided as soon as a child's needs have been identified. A pediatrician, for example, could write a prescription for physical therapy for a child with the diagnosis of cerebral palsy.

The Guma Nene program will be provided a schedule of assessments for 0-3 year old children. A member of their intervention staff will participate in the assessment. The evaluation may include:
-Cognitive
-Self-help
-Hearing
-Health
-Social/emotional
-Speech/language
-School observations
-Fine and Gross Motor
-Physical/Occupational Therapy
-Family strengths and resources
- Interviews and counseling

### 2.3 Eligibility Meeting:

An eligibility meeting will be scheduled within 5 working days after evaluations are completed. The meeting will be attended by the PEDS staff members directly involved with the family and child. At this meeting the staff will review what they have learned and determine if the child is eligible for special education services. Parents will be given the option to attend. For 0-3 year old children, a representation from Guma Nene will be invited to attend the meeting.

In order to facilitate the process of determining eligibility, the following information will be available at the meeting:
-Intake information
-Case History
-Parent surveys and questionnaires

-Evaluation reports
-Concerns and recommendations
-Test Profile form (PEDS 3.3c or 3.3d)
-Summary of Eligibility (SPF 3.3)

SEE SECTION 4.0 for Definitions and Criteria for Eligibility.

For children who are determined not to be eligible Form 3.3c will be completed. One copy will be sent to DOE and one copy to the parent. These children may be put on a monitoring system at this time.

For children who are determined to be eligible for special education services, the PEDS-CRT will turn over all evaluation reports and eligibility information to the CRT for the 0-5 programs, who will make arrangements for the placement meeting.

## 2.4 Placement Meeting:

The Placement Meeting will be scheduled within 10 days after the Eligibility meeting. This meeting may be attended by a member of the PEDS evaluation team, representatives from the most likely program placements, and the parents. It is at this meeting that the team (including the parents) will make choices among competing priorities, determine the goals and objectives, and make recommendations for type of services needed and referrals. The purpose of this meeting is to plan specific strategies, activities, and services that will result in the achievement of the expected outcomes. The most appropriate placement will also be designated at this time.

The family will have the final decision as to whether intervention services are initiated. The needs and concerns of the family will determine the expected outcomes [illegible] :ports and eligibility information will be forwarded to the receiving program.

### 2.5 Tri-Annuals:

When a 3-5 year old child is due for a Tri-Annual review, the Referral For Services form (SPF 2.5) will be sent to DOE from the CRT representing the program in which the child is currently receiving services. DOE will then transmit the referral to the PEDS. The PEDS-CRT will initiate the process of reevaluation. The process is essentially the same as the initial eligibility-placement process.

### 2.6 Case Management:

The PEDS-CRT will be responsible for case management services from the first point of contact with PEDS until eligibility or dismissal. Case management is defined in the proposed rules and regulations for PL 99-457 as "services provided to families of infants and toddlers with handicaps to assist them in gaining access to early intervention services identified in the individualized family service plan" (IFSP or IIP). Case management services are designed to reduce fragmentation and duplication in service delivery and to enable families to acquire skills for accessing, utilizing, evaluating, and advocating for services visa formal and informal resource avenues. The specific services to be provided by the case manager include:

-coordinating evaluations and referrals,
-participating in the development of the IFSP or IIP,
-assisting families in identifying available service providers,
-advocating on behalf of the needs and rights of the family,
-coordinating, monitoring, and evaluating services, and
-facilitating program transitions.

### 2.7 IFSP/IIP Development, Implementation, and Review:

The development of the Individualized Family Service Plan (IFSP) or Individualized Instructional Plan (IIP) is a process which consists of the gathering, sharing, and exchange of information between families and staff to enable them to make informed choices about the most appropriate special education services or other early intervention strategies. The process begins with the first point of contact with the professionals who are serving infants, young children, and their families. It is developed by the collaboration and partnerships between families and professionals. Information about family and child strengths, concerns, resources, and needs will be gathered at each contact with the family and modified as needed. The PEDS staff will be responsible for initiating the plan and will coordinate with the intervention programs for its completion.

Within ten (10) days of the determination of eligibility, the team shall complete the written IFSP or IIP at the Placement Meeting. Part H of Public Law 99-457 specifies the content of the IFSP and certain requirements for participation and implementation. The PEDS will follow the same guidelines for the IIP. The Plan (IFSP or IIP) shall contain the following:

-a statement of the child's present levels of physical development, cognitive development, language and speech development, psycho-social development, and self-help skills, based on acceptable objective criteria;

-a statement of the family's strengths and needs relating to enhancing the development of the family's handicapped infant;

-a statement of the major outcomes (goal and objectives) expected to be achieved for the child and family; the criteria, procedures, and time lines used to determine the degree to which progress toward achieving the outcomes is being made, and whether or not revisions of the outcome or services are necessary;

-a statement of specific early intervention services necessary to meet the unique needs of the child and family, including the frequency, intensity, and method of delivering services,

-the projected dates for initiation of services and the anticipated duration of services;

-the name of the case manager (from the profession most immediately relevant to the child's or family's needs) who will be responsible for implementing the plan and coordinating with other agencies and person;

-the steps to be taken supporting the child's transition to Part B preschool services, if appropriate.

The Plan will be implemented immediately (no later than five (5) days) after consent by the parent unless otherwise stated in the agreement. The Plan will not be implemented without parent signature documenting agreement that such services should be provided.

The Plan for each student must be evaluated once a year and reviewed by the team or teacher at least every six months. The review shall be completed by the intervention team (or teacher) and the family. It will include a discussion of each component of the IFSP to determine:

-if a component is completed and needs to be changed or halted,
-if a component is not completed, why not?,
-if the component is appropriate but not completed, what additional or modified services must be provided?,
-if the component is not appropriate, appropriate revision, and
-if additional components need to be added.

In addition to the required review, outcomes and strategies, goals and objectives will be informally reviewed and evaluated for appropriateness and effectiveness at every contact between a family and staff. Opportunities for families to evaluate an early intervention program will be integrated into program routines.

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## PEDS 1.1a - Intake Form - A

Child's Name______________________ PEDS #__________ Date__________

Date of Birth__________ Age__________ Sex [ ] Male [ ] Female

Is your child (or has s/he ever been) in a preschool program? _ Yes (Specify__________________) _No

Is this child presently receiving Special Education Services? _Yes (Specify__________________) _No

FAMILY INFORMATION

Mother______________________ Age_____ Work Phone #__________

Occupation______________________

Father______________________ Age_____ Work Phone #__________

Occupation______________________

Home Address______________________ Village__________

Mailing Address______________________

Home Phone #__________

Education

__Mother __Father

(1) < 7th grade
(2) 7th-9th
(3) 10th or 11th
(4) H.S. Graduate
(5) Some college
(6) College graduate
(7) Graduate degree

Ethnicity

__Child __Mother __Father

(01) Chamorro
(02) Filipino
(03) Micronesian
(04) Northern Marianas
(05) Other Pacific Islander
(06) Chinese
(07) Japanese
(08) Korean
(09) Vietnamese
(10) Other Asian
(11) Am. Indian
(12) Afro-American
(13) Hispanic
(14) Caucasian
(15) Other
(16) Mix

__Marital Status

(1) Married, living with spouse
(2) Common-law Relationship
(3) Single, never married
(4) Separated, divorced, or widowed

_ Military _ Civilian

__Child's First Language

(01) Chamorro
(02) English
(03) Tagalog
(04) Korean
(05) Chinese
(06) Japanese
(09) Multiple
(07) Palauan
(10) Trukese
(11) Kosraen
(12) Ponapean
(13) Marshallese
(14) Caucasian
(08) Other_____

Do you have insurance?______ If yes, what kind?__________________

Which doctor or clinic do you use for your child?__________________

When was the last time you took your child to a doctor or clinic?____

| Names of Brothers and Sisters | Age | Sex | Describe any developmental or medical concerns with these children. |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

Are there any other family members or friends living in the home? If so, who are they and what is their relationship to this child?_______

____________________________________________________________

Total number of adults and children living at home. ______ Adults

______ Children

REFERRAL INFORMATION

By whom was your child referred to Pediatric Evaluation and Developmental Services?

__(1) DOE, Teacher, School nurse

__(2) Guma Nene

__(3) Doctor________________

__(4) Public Health

__(5) Head Start

__(6) Self or family

__(7) NICU

__(8) Other__________

Please explain why this child was referred to the Pediatric Evaluation and Developmental Services.____________________________________

What is your primary concern for your child at this time?__________

____________________________________________________________

## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

### PEDS 1 2 - Consent For Screening

I hereby give my full consent for the eligibility screening of my child ______________________________ by the staff of the Pediatric Evaluation and Developmental Services Center. I understand that the following procedures may be used to determine the eligibility status of my child for special education services.

- Audiological Exam
- Case History
- Survey of Family Strengths, Needs & Resources
- Health Screening

I also hereby authorize the Pediatric Evaluation and Developmental Services Center to release this information to any physician, clinic, school agency of the Government of GUam or Federal Agency, which at the discretion of the Pediatric Evaluation and Developmental Services Center may be able to be of help or assistance to me or my child.

In executing this authorization to release the foregoing data which is in the custody of the Pediatric Evaluation and Developmental Services Center, I agree to waive any claims against the staff of the Pediatric Evaluation and Developmental Services Center for the controlled use of the data.

Signed ______________________________

Relationship: __________________________

Date: ______________________________

Witness: ____________________________

Child's Birthday: ____________________

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

PEDS 2.4 - Permission for Evaluation

Child's Name: ____________________ PEDS #: __________ Date__________

Date of Birth: ______________ Age: ______________

Part of the process of delivering Special Education services involves conducting a pre-placement comprehensive evaluation. The information gathered from this evaluation will be used to determine eligibility for Special Education and Related Services. PEDS requires your consent to conduct this pre-placement evaluation.

The individual assessment will include collecting information about your child in the following areas:

____ Cognitive/Developmental
____ Speech/Language
____ Interview/Counseling
____ Self-Help
____ Health
____ Observation: School/Home/Other
____ Social/Emotional/Behavioral
____ PT/OT - Fine and Gross Motor
____ Other

Please read the attached statement of Parents Rights in Identification, Evaluation, and Placement prior to signing this form.
It should be understood that all information collected during this evaluation will be kept confidential and will be used only by authorized personnel for the purpose of planning an appropriate education program for your child. If you have any questions, please call PEDS (734-2577).

**I have read and/or had the above information fully explained to me. I understand that a referral to Special Education is being made at this time.
I further understand that an Individual Assessment of my child has been requested.**

______ I DO GIVE permission to conduct this evaluation.
______ I DO NOT GIVE my permission to conduct this evaluation.

________________________________ Signature ________________________ Date

I have received a copy of my rights as required by P.L. 94-142 and Guam State Plan and P.L. 13-207. I have read and/or had these rights fully explained to me.

_____ Yes, I understand my rights.
_____ No, I would like further explanation of my rights.

________________________________ Signature ________________________ Date

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## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## PEDS 3.1a Developmental Profile

Name________________________________

1st Eval: Date________ Age________

2nd Eval: Date________ Age________

3rd Eval: Date________ Age________

| Developmental Level in Months | Cognitive | Language | | Receptive Language | Expressive Motor | Gross | Motor | Fine | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 39-41 | | ____ | ____ | | ____ | | ____ | | ____ | |
| 36-38 | | ____ | ____ | | ____ | | ____ | | ____ | |
| 33-35 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 30-32 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 27-29 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 24-26 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 21-23 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 18-20 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 15-17 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 12-14 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 10-11 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 8-9 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 6-7 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 4-5 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 2-3 | | ____ | | ____ | | ____ | | ____ | | ____ |
| 0-1 | | ____ | | ____ | | ____ | | ____ | | ____ |

| | | | | | |
|---|---|---|---|---|---|
| Hearing: | WNL | Mild | Moderate | Severe | Profound |
| Vision: | WNL | Partial sighted | Legally blind | Light perception | Totally Blind |

Social/Emotional: Not Significant — Highly significant
1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . 4 . . . . . . . . . 5

Self-Help: Age Appropriate — Severely delayed
1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . 4 . . . . . . . . . 5

Speech: WNL — Impaired
1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . 4 . . . . . . . . . 5

Health: WNL — Impaired
1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . 4 . . . . . . . . . 5

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## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## PEDS 3.1b Developmental Profile

Name________________________________

1st Eval: Date__________ Age_____
2nd Eval: Date__________ Age_____
3rd Eval: Date__________ Age_____

| Developmental Level in Months | Cognitive | Language | | Receptive Language | Expressive Motor | Gross | Motor | Fine | |
|---|---|---|---|---|---|---|---|---|---|
| 75-77 | | ____ | ____ | | ____ | | ____ | | ____ |
| 72-74 | | ____ | ____ | | ____ | | ____ | | ____ |
| 69-71 | | ____ | | ____ | | ____ | | ____ | ____ |
| 66-68 | | ____ | | ____ | | ____ | | ____ | ____ |
| 63-65 | | ____ | | ____ | | ____ | | ____ | ____ |
| 60-62 | | ____ | | ____ | | ____ | | ____ | ____ |
| 57-59 | | ____ | | ____ | | ____ | | ____ | ____ |
| 54-56 | | ____ | | ____ | | ____ | | ____ | ____ |
| 51-53 | | ____ | | ____ | | ____ | | ____ | ____ |
| 48-50 | | ____ | | ____ | | ____ | | ____ | ____ |
| 45-47 | | ____ | | ____ | | ____ | | ____ | ____ |
| 42-44 | | ____ | | ____ | | ____ | | ____ | ____ |
| 39-41 | | ____ | | ____ | | ____ | | ____ | ____ |
| 36-38 | | ____ | | ____ | | ____ | | ____ | ____ |
| 33-35 | | ____ | | ____ | | ____ | | ____ | ____ |
| 30-32 | | ____ | | ____ | | ____ | | ____ | ____ |
| 27-29 | | ____ | | ____ | | ____ | | ____ | ____ |
| 24-26 | | ____ | | ____ | | ____ | | ____ | ____ |

Hearing: WNL Mild Moderate Severe Profound

Vision: WNL Partial sighted Legally blind Light perception Totally Blind

Social/Emotional: Not Significant 1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . . 4 . . . . . . . . . 5 Highly significant

Self-Help: Age Appropriate 1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . . 4 . . . . . . . . . 5 Severely delayed

Speech: WNL 1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . . 4 . . . . . . . . . 5 Impaired

Health: WNL 1 . . . . . . . . . 2 . . . . . . . . . 3 . . . . . . . . . . 4 . . . . . . . . . 5 Impaired

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## 3.0 PROCEDURES (NICU Follow-Up Program):

Infants who experience neonatal difficulties are at greater risk for developmental disabilities. Families of these special care infants frequently have to cope with multiple stressors and are in need of continued support post discharge. The NICU Program is a longitudinal follow-up of the health and development of at-risk and handicapped newborns born at Guam Memorial Hospital (GMH). The CDSC staff will work closely with the Public Health-Maternal and Child Health Nurse (MCHN) to implement the program.

### 3.1 Enrollment Procedures:

The NICU follow-up program will become a part of the routine protocol for the care of special babies at GMH. This includes both in-house and post discharge activities. One staff member from the PEDS (known as the Infant Development Specialist, IDS) will be assigned to coordinate the health and developmental follow-up at GMH. The PEDS Developmental Nurse (DN) will work with the IDS. The IDS or DN will check daily with nursery personnel for information on all new admissions to the special care nurseries. The DN will fill out a risk register (PEDS 1.4) on each infant admitted and enter his/her name on the Follow-up log. They will then place a Referral Form (PEDS 1.5) in the infant's medical chart. Before an infant will be formally enrolled in the follow-up program, the referral form will be signed by the Nursery Physician.

### 3.2 Developmental Rounds:

A core team will participate in developmental rounds. The rounds will include all infants and young children to be included in the follow-up. The team will consist of at least the Physician, the IDS and the Developmental Nurse (DN). It may also include the PEDS director, Social Worker, or student intern assigned to the case.

The physician will explain each infant's medical complications, reason for admission, and any special equipment, procedures, or medication. As soon as the infant has stabilized, the physician will sign the referral form to the PEDS program which was placed in the infant's chart. The referral will signify that the baseline developmental exam may be administered. The physician will also notify the PEDS team when an infant is ready for discharge. Before discharge s/he will discuss any need for special home management plans such as home oxygen or special medications.

### 3.3 Intake:

After being notified by the physician that the infant is stable and the referral has been signed, the IDS, DN, or PEDS director will meet with the infant's family to explain the follow-up and obtain a signed consent (PEDS 1.6) to be included in the follow-up. The IDS, DN, or director will then fill out the intake form (PEDS 1.1) and administer a base line develop-mental exam. The Dubowitz Neurological Assessment of the Pre-term and Full-term Newborn Infants will be used.

### 3.4 Developmental Care in the Hospital:

The IDS or DN will also meet with the family periodically while the infant is hospitalized to discuss the infant's developmental progress and to help the parents "read" their infant's cues. Parents will be taught to carefully observe their infant, to recognize signals of stress and pleasure and to respond accordingly. There will be an emphasis on the integration of the sensory system in order for the infant to become more receptive and responsive to his/her social environment. The amount, intensity, and type of stimulation provided will be contingent on the baby's response to the stimulation and his/her capacity to tolerate stimulation.

### 3.5 Criteria for Enrollment:

The target population for the Follow-up program will be all at-risk and handicapped

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infants. Criteria for referral is listed on the Risk Register (PEDS 1.4)

In addition to infants admitted to the NICU, infants admitted to the NSCU (Neonatal Special Care Unit), well-baby nursery, or pediatric ward may be referred by a hospital staff physician or nurse. Risk status may be due to biological or environmental factors.

All infants meeting criteria will be placed on the high risk registry and be eligible for the follow-up program as an Eligibility Code #16. An informed consent for follow-up and a release of information form will be obtained from the parents. The in-take form and the risk register will be completed before the infant is discharged.

Infants not meeting specific criteria, but referred by a physician or nurse will receive a developmental screening and intake before discharge. If follow-up is indicated, the infant will be added to the risk register.

3.6 Discharge from the Hospital:

A copy of the medical discharge summary will be placed in the PEDS folder. Within two (2) days before discharge a developmental screening will be administered. The Newborn Developmental Screening (NBDS) will be used. The developmental discharge summary will be sent to the primary care physician and a copy will be included in the PEDS folder. The discharge summary will be reviewed with the primary care physician and will include the follow-up care plan. Infants with established risk will be referred for Special Education services. Before discharge the IDS or DN will arrange with the family for a home visit two to four weeks post discharge.

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### 3.7 Post Discharge Home Visit Follow-up:

The nurse and one other PEDS staff member will go on the home visit. During this visit:

- -an informed consent must be signed, if not already obtained,
- -a developmental screening will be administered
- -a case history will be taken
- -a health history and screening will be given
- -family strengths, needs, and concerns will be identified
- -the HOME scale will be completed
- -an appointment will be scheduled at the PEDS for when the infant is three to four months of age, adjusted for prematurity
- -parents will be given the Fun & Games booklet

The PEDS staff will coordinate the home visits with the Bureau of Community Health and Nursing Services at Public Health. Infants needing on-going skilled nursing home care will be referred to the Home Care program. Families needing more routine home visit follow-up will be referred to the District Nursing Program.

### 3.8 PEDS Follow-up:

At the PEDS visit, an audiological exam, a health screening and a developmental screening will be administered. High-risk infants who are developmentally age appropriate will continue on the monitoring system. Their family will be given suggestions for activities and exercises to facilitate development. For infants who meet criteria for special education services the forms and procedures described in Section 2.0 will be followed. All infants will be scheduled to return to the PEDS for developmental follow-up at 3 months, 9 months, [illegible]ths, 2 years, and yearly after that until the child is five years of age. [illegible]l be adjusted for prematurity until the evaluation at two years of a[illegible] developmental summary report will be sent to the primary care physician after each visit. With the parent's permission, pictures of the infants will be taken and posted in the Center and at the NICU.

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# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## PEDS 5.1 Intake Form (NICU)

**Child's Name**______________________ **PEDS #**__________ **Date**______

**Date of Birth**________________ **Age**_____ **Sex** [ ] **Male** [ ] **Female**

**FAMILY INFORMATION**:

**Mother**______________________ **Age**___ **Work Phone #**__________
**Occupation**________________________________________________

**Father**______________________ **Age**___ **Work Phone #**__________
**Occupation**________________________________________________

**Home Address**______________________ **Village**______________
**Mailing Address**____________________________________________
**Home Phone #**______________

### Education

____**Mother** ____**Father**

(1) < 7th grade
(2) 7th - 9th
(3) 10th or 11th
(4) H.S. Graduate
(5) Some college
(6) College graduate
(7) Grad. degree

### Ethnicity

_____**Child** _____**Mother** _____**Father**

(01) Chamorro
(02) Filipino
(03) Micronesian
(04) Northern Marianas
(05) Other Pac. Islander
(06) Chinese
(07) Japanese
(08) Korean
(09) Vietnamese
(10) Other Asian
(11) Am. Indian
(12) Afro-Am.
(13) Hispanic
(14) Caucasian
(15) Other
(16) Mix

_____Marital Status

(1) Married, living w/spouse
(2) Common law relationship
(3) Single, never married
(4) Separated, divorced,
or widowed

___ Military ___ Civilian

____Child's First Language

(01) Chamorro
(02) English
(03) Tagalog
(04) Korean
(05) Chinese
(06) Japanese
(09) Multiple
(07) Palauan
(10) Trukese
(11) Kosraen
(12) Ponapean
(13) Marshallese
(14) Yapese
(08) Other_____

Do you have insurance?______ If yes, what kind?______________
Referring Physician:______________________________________
Which doctor or clinic will you use for your child?______________

| Names of Brothers and Sisters | Age | Sex | Describe any developmental or medical concerns with these children. |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

Are there any other family members or friends living in the home? If so, who are they and what is their relationship to this child?

______________________________________________________________

Total number of adults and children living at home. ______ Adults
______ Children

## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

### PEDS 5.2 Risk Register

Subj.#.____ Name: ______________________ HOSP.#__________ D.O.B. ___
GA (LMP)_____ GA (ASSES)_________ SEX___ RACE__________ GMH NRMC
APGARS: 1___ 5___ 10___ B.W. ___g/___% LENGTH ___/___% H.C____/____%
PLURALITY: ___Singleton ___Twin ___Triplet ___>3
DELIVERY: SVD IVD C/S XC/S F
PRESENTATION: __Vertex __Breech __Other DAYS ON RESPIRATOR:__________
PARENTS:______________________________ PHONE:__________________

==================================================================

**Parental/Family Conditions**

___ Maternal age <18 >35
___ Maternal PKU
___ Mother HIV positive
___ Maternal use of anticonvulsant, antineoplastic or anticoagulant drugs
___ Parental blindness
___ Parental substance abuse
___ Parental mental retardation
___ Parental mental illness
___ Difficulty in parental/infant bonding
___ Difficulty in providing basic parenting
___ Lack of stable housing
___ Lack of familial/social support
___ Family history of childhood deafness

TOTAL P/F CONDITIONS__________

**Neonatal Complications**

___ < 1000 gms
___ < 2000 gms
___ Resuscitation at birth
___ Mechanical ventilation > 6 hours
___ Required oxygen > 7 days
___ SGA <10%; LGA <90%
___ Head Circumference <10% >90%
___ 5 min. Apgar less than 6
___ Hypoglycemia: <40 mg% >38 wks
<30 mg% <38 wks
___ Hypocalcemia: <7.5 mg
___ Hyperbilirubinemia: >20
___ Seizures
___ Suspected hearing impairment
___ Suspected vision impairment

___ Suspected IVH
___ Extreme hypo-/hypertonia
___ Hydrocephalus
___ Exchange Transfusion
___ Congenital Anomalies ___
___ Chromosomal Defect
___ Cardiac Disorder/Anomalies
______________
___ Neonatal Infection
___ Feeding Problems
___ Persistent lethargy >72 hours
___ Multiple apneic episodes
___ oral-facial anomalies

TOTAL NEONATAL COMPLICATIONS________

==================================================================

1=Normal 2=Questionable 3=Abnormal
(Results of NBDS)

_____ Habituation
_____ Attention/Interaction
_____ Motor Responses
_____ Physiological System
_____ Reflexes

______________________________
Primary Care Physician

______________________________
Clinic

Discharge Date:________________
Age at discharge____________days

TOTAL DEVEL. SCORE_________

Comments/Concerns

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# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

UOG Station
Mangilao, Guam 96923
(671) 734-2577

## PEDS 5.3 Referral Form

This section is to be completed by referring individual or agency.

Child's Name ________________ DOB ________ Sex ____

Parent's Name ________________ Home Phone ________

Residence ________________ Work Phone ________

Mailing Address ________________

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

Name of Referring Individual ________________ Date ________

Clinic ________________ Phone ________

Diagnosis ________________

________________

Reason for Referral ________________

________________

________________
Signature of Referring Individual

________________
Title

================================================================

This section is to be completed by the PEDS

The following action has been taken ________________

________________

________________

________________ / ________________
Signature Date

________________
Title

## PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

### PEDS 5.4 Agreement to Participate in Follow-Up Program

W. June Holstrum, Ph.D.
COE, Dean's Circle #17, UOG Station
Mangilao, GU 96923
(671)734-2577

Infants born prematurely or with neonatal complications often confront unique circumstan-ces as they grow and develop. Guam Memorial Hospital (GMH) and the Pediatric Evaluation and Developmental Services (PEDS) are co-sponsoring a developmental Follow-Up Program for special care infants. We are seeking your permission to monitor your child's growth and development by including him/her int eh GMH/PEDS Follow-Up Program.

The procedures are simple and entirely safe. They include the following: 1) Developmental evaluation and hearing test before charge from GMH; 2) A follow-up home visit two to four weeks post discharge; 3) Follow-up appointments at the PEDS for hearing, health and developmental evaluations when your baby is 3-4, 8-9 months, 15 months, 2 years, and yearly after that until the child is five years of age.

After each evaluation you will be given suggestions for developmentally appropriate activities for you to do with your child that are designed to facilitate your child's development. We will be happy to answer any questions you may have, prior to, during or after each evaluation. You will be informed of the results of each developmental evaluation. We will need to look at your child's hospital records to determine your child's condition at birth, treatment received, and selected background information. Your responses to the questionnaires, interview, and test results will be kept strictly confidential. There are no risks to your or your child. There is no charge for this service.

The GMH/PEDS Follow-Up Program has been fully explained to me.

I certify that I have read and understand the foregoing, that I have been given satisfactory answers to my inquiries concerning project procedures and other matters and that I have been advised that I am free to withdraw my consent and to discontinue participation in the project or activity at any time without prejudice.

Signature______________________________ Date________________
Parent/Guardian

I hereby authorize the Pediatric Evaluation and Developmental Services to have access to my child's medical records at Guam Memorial Hospital.

Signature______________________________ Date________________
Parent/Guardian

Signature______________________________ Date________________
Witness

If you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in this study, contact: Office of Graduate School and Research, University of Guam, UOG Station, Mangilao, Guam 96923. Phone: 734-3676

## 4.0 DEFINITIONS AND CRITERIA FOR ELIGIBILITY

### (01) - Developmentally Delayed:

A. Definition:

**Birth through 2 years:** "Developmental Delay" refers to infants and toddlers from birth through age 2, who:

a. are experiencing developmental delays, as measured by appropriate diagnostic/evaluation instruments and procedures in one or more of the following developmental areas: Cognitive, physical, speech/language, health, psycho-social or self-help

b. have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay, or

**Three though 5 years:** Children who are experiencing developmental delays, as measured by appropriate diagnostic/evaluation instruments and procedures in **two** or more of the following developmental areas: Cognitive, physical, speech/language, health, psycho-social, or self-help.

B. Criteria:

**Birth through 2 years:** Eligibility will be determined by developmental scores and professional judgement that indicate a discrepancy between performance age (PA) and chronological age (CA) in **one** or more of the developmental areas.

| CA | Discrepancy PA/CA |
|---|---|
| Birth - 6 months | 1 - 2 months |
| 7 - 12 months | 2 - 4 months |
| 13 - 18 months | 3 - 6 months |
| 19 - 24 months | 4 - 8 months |
| 25 - 36 months | 6 - 12 months |

**Three through 5 years:** Eligibility will be determined by developmental test scores and professional judgement that indicate delay in **two** or more of the developmental areas:

| CA | Delay |
|---|---|
| 3 - 4 years | 6 - 12 months |
| 4 - 5 years | 8 - 12 months |

**(03) - Mentally Handicapped:**

A. Definition:

Significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period which adversely affects a child's educational performance.

B. Criteria:

Intellectual functioning: Two (2) standard deviations) or more below the mean. Adaptive behavior: Must reflect objective documentation through the use of an established scale and appropriate behavior/anecdotal records.

**(05) - Hearing Impaired:**

A. Definition:

A hearing impairment, whether permanent or fluctuating, which adversely affects a child's educational performance but which is not included under the definition of "deaf".

B. Criteria:

0 through 5 years, 25 dB pure tone average or worse in the better ear (pure tone average includes 500, 1000, and 2000 Hz.

6-21 years, 30 dB pure tone average or worse in the better ear (pure tone average includes 500, 1000, and 2000 Hz.

Slight: 20 - 25
Mild: 26 - 40
Moderate: 41 - 55
Moderate/Severe: 56 - 70
Severe: 71 - 90
Profound/Deaf: 91 or greater

NOTE: Any child who has an AIR-BONE GAP at the 500, 1000, 2000 Hz in the better ear or any child with an abnormal and flat tympanograms in the better ear must have an audiological reevaluation and hearing handicap status reviewed within six months.

**(06) - Deaf:**

A. Definition:

A hearing impairment which is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, which adversely affects educational performance.

B. Criteria:

Hearing loss greater than 90 dB pure tone average or worse in the better ear.

**(07) - Visually Handicapped:**

A. Definition:

A visual impairment which, even with correction, adversely affects a child's educational performance. The term includes both partially seeing and blind children.

B. Criteria:

Partially sighted (20/70 - 20/200)
Legally blind (Less than 20/200; or visual field of less than 20 degrees
Light perception only
Totally blind

**(08) - Communication Disorder:**

A. Definition - Speech Disorder:

**Speech Disorder:** Impairment of the speech act which interferes with intelligible speech production and is observable in the transmission and use of the oral symbol system. Impairment may occur in the areas of voice, resonance, articulation of speech sounds, and/or fluency.

**Language Disorder:** Impairment or deviant development of understanding (receptive) and/or using (expressive) spoken or written language, and/or other symbol systems, including (1) the form of language (phonologic, morphologic, and syntactic systems), (2) the content of language (semantic systems), and/or (3) the function of language in communication (pragmatic system).

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B. Criteria:

**Speech Disorder:** When indicated by objective speech test results (when appropriate) and/or when listener judgement deems speech production as unintelligible or deviant from normative expectations for the speaker's age group.

**Language Disorder:** Language test scores indicate a delay in Language Age (LA) of:

| CA | Delay |
|---|---|
| 3 to 4 years | 6 - 12 months |
| 4 to 5 years | 8 - 12 months |
| 6 to 8 years | 18 months or greater |

**(NOTE) Speech-Language Difference: No child should be classified as having a "Communication Disorder" whose speech or language difference may be attributable to cultural, ethnic, bilingual, or dialectical differences, or being non-English or limited-English speaking. "Speech-Language Difference" is defined as a variation of a symbol system (language) used by a groups of individuals which reflects and is determined by shared regional, social, or cultural/ethnic factors.**

**(09) - Orthopedically Impaired:**

A. Definition:

A severe orthopedic impairment which adversely affects a child's educational performance. The term includes impairments caused by congenital anomalies, impairments caused by disease or accidents, and impairments from other causes.

B. Criteria:

Physical and/or Occupational Therapy evaluation indicates the child's motor performance deviates from normative expectations. A child must be classified as having an orthopedic impairment if the condition involves muscles, bones, or joints and is characterized by impaired ability to maneuver in the classroom or home environment; impaired ability to perform fine or gross motor activities; or impaired ability to perform self-help.

**(10) - Health Impaired:**

A. Definition:

Limited strength, vitality, or alertness due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes which adversely affects a child's educational performance.
Health impairment may also include severe dental problems when the condition of the teeth and supporting structures is such that routine eating is restricted or impossible; chronic pain is evident; growth and development are delayed or retarded; speech is impacted; and the child cannot perform daily activities and needs special schedules and services.

B. Criteria:

Eligibility shall be determined by the judgement of a multi-disciplinary team consisting of professionals qualified to make a health and educational diagnosis.

**(11) - Deaf/Blind:**

A. Definition:

Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational problems that they cannot be accommodated in special education programs solely for deaf or blind children.

B. Criteria:

Eligibility will be determined by the same criteria as used for the specific categories in 05, 06, and 07.

**(12) - Multiply Handicapped:**

A. Definition:

Concomitant impairments (such as mentally retarded-blind, mentally retarded-orthopedically impaired, etc.), the combination of which causes such severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments. The term does not include deaf-blind children.

B. Criteria:

Eligibility will be determined by the same criteria as used for each specific handicapping condition.

**(16) - At Risk:**

A. Definition

An infant or child (0-3) who exhibits characteristics, or is exposed to risk factors which are likely to cause a developmental delay if no education instruction is provided including factors related to:

- -biological characteristics such as inadequate emotional, postnatal risk factors; and
- -environmental characteristics such as inadequate emotional, family or health care; economic deprivation; and inadequate opportunities to learn adaptive behavioral and other social skills.

(**Note:** Infants assigned a Code #16 will be put on a monitoring system. This would involve periodic testing. It may or may not include periodic contacts by phone or home visit. IFSPs will not be completed for Code #16 children.)

B. Criteria:

One or more items checked on the risk register (PEDS 5.2).
Professional judgement

## 5.0 DATA BASE

A comprehensive data system will be established which will include all infants and young children referred to the Center. At a minimum the following information will be collected and maintained in the data base system:

- number of children referred
- referral sources
- reasons for referral
- demographic data
- number of children assessed
- number of children referred assigned to each eligibility category
- outcome data, such as assessment results
- number of children for whom services are terminated

## 6.0 TRAINING

### 6.1 Management of Supervision of Practicum Students and Interns

The PEDS Director is the responsible person to oversee the referral, placement, management and supervision of all practicum students, observers, and interns assigned to the PEDS Center located at House #17 Dean's Circle, University of Guam. The CDSC Director may assign individuals to qualified staff personnel working within the clinic as deemed necessary to provide the required learning opportunities, and determine the maximum number of students who may complete requirements at any one time.

Clinical Fellowships will be available to Speech-Language Pathologists and Audiologists wishing to complete their Clinical Fellowship Year (CFY) at the PEDS. They will be supervised by professionals holding a current Certificate of Clinical Competence (CCC) in Speech-Language Pathology or Audiology. Supervisors are ASHA certified and Guam licensed Speech-Language Pathologist or Audiologist.

Practicum students and interns interested in the screening, assessment and evaluation of infants, toddlers, and preschool children are referred to the PEDS Director. They will be supervised by the PEDS staff at the Center, during home visits, and visits to other agencies.

Students interested in health and medical aspects of infants, toddlers and preschoolers are referred to the PEDS Director. They will be supervised by the PEDS Director and the a neonatal/pediatric nurse.

Students interested in infant, toddler, and preschool classes and direct intervention services are referred to the DOE Early Childhood Special Education Administrator. The Administrator places the student in an appropriate practicum or student teaching setting with a master teacher or supervisor or teacher who is responsible for the management and supervision of the student teacher.

Students interested in internships in normal Speech-Language Development and/or Communication Disorders are referred to an ASHA certified and Guam licensed Speech-Language Pathologist or Audiologist located at the PEDS Center.

Academic instruction and professional behavioral ethics of students assigned to PEDS are the responsibility of the supervising faculty from their respective departments, i.e. School of Nursing and Allied Health, Clinical and Human Services Department of the University of Guam. The responsible faculty will help to facilitate the placement, management, and supervision of student teachers with the collaboration of the PEDS Director, staff, and DOE personnel when deemed appropriate.
Student teachers shall not be used to function in any way as employed staff personnel within PEDS.

The maintenance of teaching responsibilities and the completion of course

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requirements is the responsibility of the supervising faculty in consultation with the PEDS Director or responsible staff and DOE when deemed appropriate.

Evaluation of student teachers is a cooperative effort between the PEDS Director or responsible staff, faculty, and DOE when deemed appropriate. Progress standards are negotiated by the responsible personnel from PEDS, DOE, and the University.

6.2 Necessary Qualifications for the responsible PEDS or DOE Cooperating Master Teacher:

Cooperating master teachers shall hold master's degree or equivalent thereof (30 graduate credits) in early childhood education or special education with at least two years of teaching experience.

Cooperating PEDS and DOE staff personnel who are working with student teachers in fulfilling observation or other course requirements shall have the minimum requirements of a bachelor's degree in the appropriate area with at least two years work experience with handicapped or at-risk infants and toddlers, or with handicapped preschool children.

## 7.0 PROCEDURES FOR CONDUCTING RESEARCH WITHIN THE PEDS:

University faculty, staff, and students as well as professionals from other agencies interested in conducting research at PEDS shall make a written application to the PEDS director. The investigator shall submit the completed CHRS FROM A, a copy of the entire proposal, and copies of any consent forms. The PEDS director and staff will review the proposal. After approval is granted from the PEDS staff and director, the proposal and recommendations will be forwarded to the University of Guam Committee on Human Research Subjects (CHRS).

All projects which involve human subjects and which are conducted at or sponsored by the University of Guam, regardless of the absence or presence of support, and regardless of who else may have reviewed them, must receive prior approval from the CHRS, which will serve as the Institution Review Board (IRB).

The Chair of the CHRS will appoint an Ad-Hoc Committee from its membership to review and provide recommendations to the membership. Approval of the proposal shall be by the concurrence of a majority of the members present. Any proposal not approved by the HRS may be reconsidered if additional information or revisions are submitted by the investigator.

Application to the PEDS director and the Human Subjects Committee for permission to conduct research shall be in written format. The research proposal shall include descriptions of the following:

- -statement of the problem
- -purpose, goals, objectives, and hypotheses
- -rationale
- -theoretical framework
- -review of current literature/research
- -methodology and research design
- -procedures for data collection and analyses
- -form for informed consent
- -implications for PEDS and education research
- -qualifications of the researcher(s)

Researchers shall follow the rules and regulations governing behavior of professionals at the PEDS. Parents of potential participants shall be informed in writing of the study to be conducted. Parents have the right to grant or deny permission to include their child in the research study.
Acknowledgement of parental approval for participation in the study shall be in writing and kept of file at the PEDS.

## 8.0 PROCEDURAL SAFEGUARDS

All services provided by Pediatric Evaluation and Developmental Services must be implemented in ways that protect the family from intrusion and coercion. Safeguarding families involves at least four considerations:

**Privacy** Families have a right to privacy. All services provided must be implemented and evaluated in ways that protect privacy at all times. Only information that a family thinks is necessary with respect to identified needs, stated outcomes, and courses of action should be included in the IFSP.

**Confidentiality** No information about a child or family, written or verbal, can be shared with anyone without the family's permission and informed consent.

**Full disclosure of information** Families must have full access to any and all information. This includes assessment information, existing records, and new data gathered as part of the process.

**The family's right to decide about all aspects of their child's program.** Families have the final decision in all matters regarding their children. Families may invite persons of their choosing to be part of their IFSP team and to help determine the key "players" in the development and implementation of their IFSPs.

The PEDS will also follow the procedural safeguards that are included in Part H of Public Law 99-457. These safeguards are listed below:

-The timely administrative resolution of complaints by parents.
-The right to confidentiality of personally identifiable information.
-The opportunity for parents or guardians to examine records relating to assessment, screening, eligibility, and the development and implementation of the IFSP (or IEP).
-Procedures to protect the rights of the infants and toddlers if the parents or guardian of the child are not known or are unavailable or if the child is a ward of the state.
-Written prior notice to the parents whenever the state agency or provider proposes or refuses to initiate or change the identification, evaluation, placement, or provision of appropriate early intervention services. This written notice must be in the parents' native language, unless it clearly is not feasible, and must inform parents of all the procedures they have available to them under this Section.
-During the time a proceeding or action involving a complaint is underway, unless the state agency and parents agree otherwise, the child shall continue to receive the early intervention services currently being provided or, if applying for initial services, shall receive the services not in dispute.

## 9.0 LIST OF COMMONLY USED FORMS AND PROTOCOLS

A Parenthesis after a PEDS form indicates the page on which the form can be found. SPF forms can be found in the HANDBOOK for the DELIVERY of SPECIAL EDUCATION SERVICES.

### 9.1 Intake

| | |
|---|---|
| PEDS 1.1a | Intake Form (8) |
| PEDS 1.2 | Consent for Screening (10) |
| PEDS 1.3a | Case History |
| PEDS 1.3b | Background Information |
| | Family Needs Survey |
| | Family Support Scale |

### 9.2 Case Review

| | |
|---|---|
| SPF 2.4b | Parent's Rights |
| PEDS 2.4 | Permission for Evaluation (11) |

| | |
|---|---|
| SPF 2.5 | Referral for Services-Internal Form |
| SPF 1.1.2c | Release of Information |

### 9.3 Eligibility

| | |
|---|---|
| SPF 6.3.3 | Case Manager Notes |
| PEDS 3.1a | Developmental Profile (0-41 months) (12) |
| PEDS 3.1b | Developmental Profile (24-77 months) (13) |
| | McCarthy Profile |
| | WPPSI Profile |
| SPF 3.3 | Summary of Eligibility and Determination Evaluation Reports |
| SPF 3.3c | Child Ineligible for Services |

### 9.4 Placement

| | |
|---|---|
| SPF 4.1 | Parent Notification |
| SPF 4.2.2 | IIP: Current Functioning |
| SPF 4.2.3 | IIP: Goals and Objectives |
| SPF 4.2.4 | IIP: Placement |
| SPF 4.2.4a | IIP: Related Service Addendum |
| SPF 4.2.4b | IIP Addendum: Description of Consultant Services |
| SPF 4.2.5 | Parent Notice: Consent for Initial Placement in Special Education |

### 9.5 NICU Follow-Up Forms

| | |
|---|---|
| PEDS 5.1 | Intake Form (NICU) (17) |
| PEDS 5.2 | Risk Register (19) |
| PEDS 5.3 | Referral from Hospital or Clinic (20) |
| PEDS 5.4 | Consent for Follow-Up Program (21) |
| PEDS 5.5 | Developmental Progress Notes |
| | Premie Growth Chart |
| | Dubowitz Protocol |
| | Newborn Developmental Scale (NBDS) |
| | HOME Scale |

University of Guam
Unibetsedat Guahan
University Affiliated Program
House #11 Dean's Circle
College of Education UOG Station
Mangilao, Guam 96923

Tel 671-734-9309 • 734-6531
Fax 671-734-5709 • E-Mail heidisan@uog edu • sspencer@uog edu

University Affiliated Program
On Developmental Disabilities

November 30, 1995

MEMORANDUM

TO: University of Guam
    College of Nursing -via. M. Fochtman
    Pediatric Evaluation and Developmental Services Center -via M. Blaz
  Guam Memorial Hospital
    Administrator -H. Ripple
    Staff Development Coordinator-W. Cando
    Director Maternal and Child Health Nursing- A. Ahern
  SDA Clinic- via W. Vercio, cc. L. Meadows
  The Doctor's Clinic- via F. Lizama
  Pacific Care Medical Clinic- via B. Rada
  Harmon Pediatric Clinic- via Y. Carrera
  Dededo Poly Medic- via M. Esperanza
  Naval Hospital- via D.W. Kern, cc. J. Campbell
  FHP Clinic- J. Stadler
  Pediatric Clinic- via. T. Nixt
  Central Medical Clinic- via W. Chen
  Public Health and Social Services Bureau of Nursing- via F. Carbullido
  Guam Developmental Disabilities Council- via T. Paulino
  Department of Education Part H Program (Infant and Toddler) -via. L. Nishimura

FROM: Heidi Farra-San Nicolas, Ph.D.
Director, UAP
Professor of Special Education

SUBJECT: Follow-Up Information, Materials and Evaluation of Dr. Allen Crocker's Visit

Attached is a summary of evaluations from Grand Rounds held at Guam Memorial Hospital on October 25 in addition to evaluations provided by your clinic's round table discussion held with Dr. Crocker later that same week. Please share the resources and evaluations with colleagues at your clinic who participated in Grand Rounds and or the round table discussions. We hope that the feedback will provide you with a basis for discussion, and may lead to additional activities in the future. On behalf of the Guam UAP and Dr. Allen C. Crocker of the Boston UAP, we would like to thank you for participating in the week long series of activities. The outcomes from the Grand Rounds, the individual clinic round table sessions, and meetings with the College of Nursing, Pediatric Evaluation and Developmental Services Center, Naval Hospital and the Guam Legislature gave the Guam UAP, the Guam Developmental Disabilities Council and the DOE Part H Program valuable information on the needs of children with developmental disabilities including specific medical needs.

We anticipate that a follow-up session focusing on medical needs of children with developmental disabilities will be held in late Spring (possibly April or May). The venue, specific focus and funding sources are currently being investigated and planned, and we welcome your input and suggestions.

Enclosed is a copy of ***Developmental Disabilities, Delivery of Medical Care for Children and Adults*** by Dr. Leslie Rubin and Dr. Allen C. Crocker. We hope you find this useful in your work with children who have developmental disabilities. Also enclosed is a set of extra assessment protocols for the Infant Developmental Screening Scale distributed to you during the Round Table Sessions as well as additional handouts from Allen Crocker. We encourage you to continue to refer children to our Pediatric Evaluation and Developmental Services (PEDS) Center when you suspect that the child may have a disability, or may be at-risk for developing disabilities should intervention services not be delivered. The PEDS Center is located at House #17 Dean's Circle, just a few houses from the UAP (Houses 11 and 18) and the Guam System for Assistive Technology (GSAT) Center. The Guam System for Assistive Technology is also part of the UAP and is located at House #12. Contact numbers for PEDS are : 735-2455- 56. Contact numbers for GSAT are: 735-2490-95.

Also enclosed is an article by Dr. Crocker that appeared in the journal, ***Developmental and Behavioral Pediatrics.*** Dr. Crocker was formerly President of the Society for Behavioral Pediatrics and shared a collection of children's poetry as his outgoing farewell remarks. We thought that you may also enjoy the collection.

On Friday afternoon, October 27th, Dr. Crocker summarized reflections of his the week long visit to Guam during a special session with the Guam Legislature Committee on Health, and Committee on Education. Allen was impressed with the dedication of individuals on Guam, the earnestness of the approach to health care, and found no inadequate devotion. He enjoyed the warmth, and family and community orientation of the island. He found pediatricians to be stressed, and placed into a position of being a jack of all trades, but was impressed that physicians turn to each other for support and resources. He found much praise and support for the services offered by PEDS, and felt that having visited with both hospitals and all the major clinics, and Public Health and Social Services, that he gained a fair assessment of the status of medical supports for individuals with developmental disabilities on island. He outlined seven major areas of needed improvement. These included:

1. The absence of an agency or department for MR/DD which he stated would be a continuing liability for the island as there is currently no place that coordinates services.
2. There was much criticism in lack of support and systems to enable inclusion to work. While inclusion itself is a good move, parents and medical professionals report that the supports are not in place and children are not being adequately served, and that there is not enough communication between medical and educational professionals.
3. The absence of medical resources on island including pediatric neurology, genetics, pediatric cardiology, neonatology, clinical child psychology, and a lack of access to magnetic resonance imaging (MRI). Also the lack of on-island behavioral treatment programs.
4. The need to better support the integrity of the family including support to parents, and the need to enhance and promote support groups for parents of children with disabilities (ie. PAN, Parents and Agencies Networking).

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5. The lack of an effective and efficient Public Health tracking system or registry for birth defects, epidemiology, and metabolic screening. Data on obesity, diabetes, and hypertension are of only medium satisfaction and should be addressed as well as the low birth weight, prenatal care, and out-of-wedlock rates.
6. The need to reduce the politics in health care (ie. appointment of health officials, and standards and policies) on Guam.
7. The plight of individuals immigrating from the Compact States and their need for truth, justice and rightness.

Thank you, again, for participating in the above mentioned activities. We look forward to future collaborative events that will lead to improvements in the lives of individuals with developmental disabilities.

## UNIVERSITY OF GUAM
### University Affiliated Program (UAP)

Round Table Session
with Allen C. Crocker, M.D.
October 25-27, 1995

LOCATION PEDS

## EVALUATION FORM

# 21 Evaluation Forms

Instructions: Circle the number that best describes your feedback. The information you provide will help the UAP to improve future activities.

---

| | | Strongly Agree—Agree—Disagree | Mean |
|---|---|---|---|
| 1. | The session was appropriately structured to address needs of our clinic or program. | 5 4 3 2 1 | 4.5 |
| 2. | I feel more knowledgeable about good practices in the diagnosis and management of developmental disabilities and related conditions in rural and remote areas. | 5 4 3 2 1 | 3.8 |
| 3. | I feel more knowledgeable about the need for patient education resulting in the prevention of developmental disabilities and of related secondary conditions in children and adults. | 5 4 3 2 1 | 4.2 |
| 4. | I have a better awareness of the need for communication across disciplines and between parents and myself as a medical professional. | 5 4 3 2 1 | 4.3 |
| 5. | I believe that the reference books, assessment tool, and other information distributed during the session will be helpful and used on-site. | 5 4 3 2 1 | 3.6 |
| 6. | The on-site Round Table structure was an effective method of delivery for technical assistance. | 5 4 3 2 1 | 4.4 |
| 7. | This session has significantly increased my clinical skills in working with children and adults who have developmental disabilities. | 5 4 3 2 1 | 3.6 |

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See attached Forms

## Round Table Session with Dr. Allen C. Crocker
Page 2 of 2

8. I would like to see additional sessions held on the following topics:

9. The most valuable aspect of this Round Table was:

10. I wish that additional information was included on:

11. Other comments or feedback to the UAP:

## UNIVERSITY OF GUAM
## University Affiliated Program (UAP)

**Round Table Session**
**with Allen C. Crocker, M.D.**
**October 25-27, 1995**

**LOCATION** PEDS

## EVALUATION FORM
***Comments***

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1. **I would like to see additional sessions held on the following topics:**

- Child Abuse, disabled children.
- Updated knowledge on different medically contributory factors for disability.
- A longer session to ask questions.
- New methods/strategies of practice with developmentally delayed kids.
- Evaluation tools to use on developmentally delayed population (valid).
- Infant Mental Health Dx, Intervention, Education, Pediatric neurology, Pediatric head trauma.
- More information on specific medical areas, and new technology to use in the home and play group setting.
- Approaches dealing with parents.
- Specific strategies on patient/client management family.
- Different syndromes, AIDS.
- Syndromes, Disabilities.
- Information on low incidence developmental evaluation.
- More discussion on the characteristics listed for eligibility into the infant toddler program.
- Strategies for children with developmental disabilities, Seizures, Diagnosis of CP.

2. **The most valuable aspect of this Round Table was:**

- Shared information.
- Follow up text.
- Dr. Crocker's knowledge base.
- Comparison of the State Plan. Everything discussed was interesting and appropriate.
- That is was informal.
- The sharing of information and concerns as well as the opportunity to network.
- Accessibility to experts as part of group discussion, not lecturer and audience format.
- Open discussion, availability to ask questions.
- Overall interesting but not specific enough.
- One on one with Dr. Crocker and having him answer specific questions.
- The comfortable atmosphere that we were able to ask questions and to state our professional opinions. (No Breaks!)
- The informal atmosphere that encouraged free conversation with Dr. Crocker.
- Session at PEDS - felt material discussed was more practical and relevant for my purposes.

- Small groups, one on one interaction, given an eligible of another state plan and implementation.
- Insight to Part H.
- Understanding how other locations handle eligibility.
- Awareness.

3. **I wish that additional information was included on:**

- Autism.
- Medical aspects.
- Expanding what was presented, not enough time.
- More information.
- New techniques and not necessarily increase information, but just more time for questions and answers.
- Implications (correlations) of medical conditions in early infancy on later development across the obvious domains (e.g., jaundice, isolated episodes of dehydration, seizures, etc.)
- We needed more time with Dr. Crocker.
- Handouts for parents.

4. **Other comments or feedback to the UAP:**

- I would have learned more if we had more time for discussions. Dr. Crocker's input. It was actually nice that Dr. Crocker heard and feels that we are doing a good job since comments like that are seldom heard by us.
- Please keep up with more continuing conditions for our program in order to serve our kids very well and to the utmost of our ability.
- I would like to see Dr. Crocker back for a workshop.
- Great appreciation!
- Number 5 was not really addressed.
- UAP has organized excellent TA activities! The UAP should be maintained as the entity to develop and organize future TA's!
- Please continue to provide more sessions like this.
- The instructor was very informative and the session was comfortable and informal.
- Interdisciplinary and united agency round tables!

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## Intake Information

Peds No: 2466 Name: DUSABAN, CHARILYN Date: 09/02/93

DOB: 05/30/92 Age: 1 YEAR 3 MONTHS Sex: F

Enrolled in Preschool Program: NO In Special Education Program: NO

If yes, name of program: N/A

---

Mother's Name: DUSABAN, CHONA Work Phone:

Father's Name: LEONES, ROBERT Work Phone:

Home Address: 150 KALAMASA ST. DEDEDO,

Mailing Address: P.O. BOX 9458, DEDEDO, GUAM 96912.

Home Phone: 632-2530

---

Ethnicity:

Child: FILIPINO

Mother: FILIPINO

Father: FILIPINO

Child's Primary Language: ENGLISH

---

Insurance: NONE

Physician/Clinic: DR. CHEN

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

**PEDS #:** 2466 **Name:** Charilyn Dusaban **Date of Birth:** 05/30/92

**Date of Assessment:** 09/02/93 **Chron. Age:** 15 months, 12 days

**Parents:** Robert Leones & Chona Dusaban **Phone:** 632-2530

**Reason for Referral:** Charilyn was referred for a developmental assessment as part of the PEDS/GMH follow up program. She was initially enrolled in the program due to lack of prenatal care and maternal age.

**Primary Parental Concern:** Ms. Dusaban did not express any specific concerns at this time in regards to her daughter's development.

## I. PERTINENT BACKGROUND INFORMATION

For information concerning Charilyn's early prenatal development and medical history, see report dated 02/09/93. Since initial interview, Charilyn has been healthy except for an occasional cold and fever. Charilyn is presently being given Enfapro formula both from a bottle and a cup. According to her mother, Charilyn is a picky eater. She enjoys eating noodles, rice and soup and soft vegetables. Charilyn is able to sleep through the night.

## II. CHILD EVALUATION REPORTS

A. **Audiological Report**: **Date:** 9/2/93 **Age:** 15 months, 2 days

**Name:** Charilyn Dusaban **DOB:** 5/30/92

Sound-field testing, which is a test of the better ear, indicated hearing within normal limits for warble tones (500 to 4000 Hz).

Tympanograms, which indicate middle-ear function, were within normal limits bilaterally. No further audiological follow-up is needed at this time.

Renee L.G. Koffend, M.S., CCC-A
Audiologist

arents

UNIVERSITY OF GUAM
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*Pediatric Evaluation and Developmental Services*
COE, Dean's Circle #17
UOG Station
Mangilao, Guam 96923

# DEVELOPMENTAL EVALUATION REPORT

For

Charilyn Dusaban

Intake
I. PERTINENT BACKGROUND INFORMATION
II. CHILD EVALUATION REPORTS

Submitted By:

Susan D. Hokanson, M.Ed., Service Coordinator

Renee L.G. Koffend, M.S., CCC-A

Sandra D. Leon

Tel: (671) 734-2577 or 734-9174 FAX: 734-7820

B. Developmental Summary Report: **Date:** 09/02/93 **Age:** 15 months, 2 days

**Name:** Charilyn Dusaban **DOB:** 05/30/92

Assessment Observations:
Charilyn was accompanied to the testing site by her mother and grandmother. She appeared to be a healthy toddler who was nicely dressed and well groomed. Charilyn showed no signs of apprehension to the testing situation and interacted appropriately with the examiner. Testing was completed with Charilyn seated on her mother's lap at the small table. She attempted all test items presented to her and appeared to enjoy playing with them. Gross motor items were based on mother's report and casual observation. Social smiles were observed and a few true words were heard during the assessment. Mother conversed freely with the examiner.

Tests Administered:

Island Infant/Toddler Screening Instrument (IITSI)
Bayley Scales of Infant Development (BSID)

Developmental Assessment Summary:

At the time of testing Charilyn had a chronological age of 15 months, 2 days. She was developmentally within normal limits in all areas tested. Assessment resulted in the following estimates of developmental ranges.

| | IITSI | | BSID |
|---|---|---|---|
| Mental/Social: | 18.0 - 20.0 months | Mental: | 16.0 - 18.0 months |
| Language: | 18.0 - 20.0 months | Motor: | 17.0 - 19.0 months |
| Fine Motor: | 17.0 - 19.0 months | | |
| Gross Motor: | 19.0 - 21.0 months | | |

**MENTAL/SOCIAL:** Charilyn was able to follow simple directions, use her pointer finger to point at what she wants and show her shoe when asked. According to her mother, she was able to play by herself for 5-10 minutes, point to 4 body parts and likes to "help" with housework. She was unable to use a stick to get what she couldn't reach, follow specific directions when playing with a doll or find both toys hidden under two cups.

**LANGUAGE:** Charilyn was able to attempt to imitate words said to her and say the name of at least one object seen in a book (fish). According to her mother, she was able to say "oops" when something happens, say "no" and know what it means and understand and use 10 different words. Charilyn was unable to make correct sounds for familiar animals, understand and use 20 different words or make two-word sentences.

**FINE MOTOR:** Charilyn was able to mark on paper, imitate drawing a line and put the lid back on the box. She was unable to stack at least three small blocks, partially complete a puzzle or unscrew a lid.

**GROSS MOTOR:** According to her mother, Charilyn was able to stand on one foot while holding on, climb into an adult sized chair, run across the room without falling and kick a big ball. She was unable to throw a sponge ball into a box that is 2-3 feet away, walk on or near the rope at least 6 feet or jump off the floor with both feet.

**BEHAVIOR:** Charilyn was a pleasant toddler to test. She tolerated the entire evaluation without any signs of fussiness. According to her mother, she is still an easy child to care for. Ms. Dusaban also reported that Charilyn enjoys watching Barney videos.

## C. **Summary and Recommendations**:

Summary of Family/Child Concerns, Priorities, and Resources:
**Ms. Dusaban did not express any specific concerns at this time in regards to her daughter's development. Charilyn is currently functioning within normal limits in all areas of development tested today. It appears as if she is being provided with the appropriate stimulation needed to encourage her development.**

**Therefore, it is recommended that:**

1. Charilyn continue to be monitored as part of the PEDS/GMH follow up program. Her next scheduled evaluation will be in June, 1994, when she is 2 years old. **The family will be contacted for an appointment at that time.

2. Charilyn's family continue to encourage her development in all areas. Some suggested activities and developmental guidelines were given to the mother today.

Susan Yasuhiro
Susan Y. Yasuhiro, M.Ed.
Early Childhood Specialist

Sandra Leon
Sandra D. Leon
Early Childhood Specialist

cc: Parent
Dr. W.Y. Chen

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

## Intake Information

Peds No: 2466   Name: DUSABAN, CHARILYN   Date: 07/06/94
DOB: 05/30/92   Age: 2 YEARS 1 MONTH   Sex: F
Enrolled in Preschool Program: NO   In Special Education Program: NO
If yes, name of program: N/A

Mother's Name: DUSABAN, CHONA   Work Phone:
Father's Name: LEONES, ROBERT   Work Phone:
Home Address: 150 KALAMASA ST. DEDEDO,
Mailing Address: P.O. BOX 9458, DEDEDO, GUAM 96912
Home Phone: 632-2530

Ethnicity:
Child: FILIPINO
Mother: FILIPINO
Father: FILIPINO
Child's Primary Language: ENGLISH

Insurance: HML
Physician/Clinic: CENTRAL MEDICAL CLINIC

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*Pediatric Evaluation and Developmental Service*
COE, Dean's Circle #17
UOG Station
Mangilao, Guam 96923

COPY

# DEVELOPMENTAL EVALUATION REPORT

For

Charilyn Dusaban

Intake
I. PERTINENT BACKGROUND INFORMATION
II. CHILD EVALUATION REPORTS

Submitted By:

Susan Y. Yasuhiro, M.Ed., Service Coordinator

Renee L.G. Koffend, M.S., CCC-A

Sandra D. Leon

# PEDIATRIC EVALUATION and DEVELOPMENTAL SERVICES

**PEDS #:** 2466 **Name:** Charilyn Dusaban **Date of Birth:** 05/30/92

**Date of Assessment:** 07/06/94 **Chron. Age:** 25 months, 6 days

**Parents:** Chona Dusaban & Robert Leones **Phone:** 632-2530

**Reason for Referral:** Charilyn was referred for a developmental assessment as part of the PEDS/GMH follow up program. She was initially enrolled in the program due to lack of prenatal care and maternal age.

**Primary Parental Concern:** Ms. Dusaban did not express any specific concerns at this time in regards to her daughter's development.

## I. PERTINENT BACKGROUND INFORMATION

For information concerning Charilyn's early prenatal development and medical history, see reports dated 02/09/92 and 09/02/93. Since the previous assessment, Charilyn has been healthy except for an occasional cold. According to her mother, she is presently up to date with her immunizations. Her mother also reported that she is occasionally picky about eating. Charilyn, reportedly, uses a bottle at night.

## II. CHILD EVALUATION REPORTS

A. Developmental Summary Report: **Date:** 07/06/94 **Age:** 25m, 6d

**Name:** Charilyn Dusaban **DOB:** 05/30/94

Assessment Observations:
Charilyn was accompanied to the testing site by her mother. She appeared to be a healthy child who was nicely dressed and well groomed. Charilyn was slightly apprehensive at the beginning of the evaluation. She required a few minutes to adjust to the new situation. Testing was completed with Charilyn seated at small table. Her mother sat to the side of her. She attempted all items presented to her. Verbalizations were not heard and many of the language items were based on mother's response. Social smiles were not observed. Mother spoke freely with the examiners.

Tests Administered:

Island Infant/Toddler Screening Instrument (IITSI)
Bayley Scales of Infant Development (BSID)

## Developmental Assessment Summary:

At the time of testing Charilyn had a chronological age of 25 months, 6 days. She was developmentally within normal limits in all areas tested. Assessment resulted in the following estimates of developmental ranges.

| | IITSI | | BSID |
|---|---|---|---|
| Mental/Social: | 23.5 - 26.5 months | Mental: | 26.0 - 28.0 months |
| Language: | 27.0 - 30.0 months | Motor: | 26.0 - 28.0 months |
| Fine Motor: | 28.0 - 31.0 months | | |
| Gross Motor: | 24.5 - 27.5 months | | |

**MENTAL/SOCIAL:** Charilyn was able to point to more than three pictures in a book. According to her mother, she was able to wait 2-3 minutes to get what she wants and play pretend. She was unable to find both toys hidden under two cups, match two things that were the same color or tell if she was a boy or girl.

**LANGUAGE:** According to her mother, Charilyn was able to use words to ask for what she wants, sing parts of songs by herself, use 3-5 words sentences and name at least 8 pictures in a book. Her mother also reported that she was beginning to say her first and last name. Charilyn was unable to understand what objects are used for, tell about a picture she has drawn or understand prepositional usage.

**FINE MOTOR:** Charilyn was able to hold a crayon between her fingers and thumb, scribble in a circular motion and complete a three piece puzzle. She was unable to stack 8 or more blocks, copy a circle or cut a piece of paper into two pieces.

**GROSS MOTOR:** Charilyn was able to kick the ball, stand briefly on one foot and throw the ball forward. According to her mother, she was able to jump off the floor with both feet. Her mother also reported that she was unable to walk on tip-toes, walk backwards at least 8 feet or walk on the rope for 10 feet.

**BEHAVIOR:** Charilyn was a pleasant child to test. She tolerated the entire evaluation without any signs of fussiness. Charilyn is described by her mother as being in the "terrible two's" stage. She enjoys playing, watching Barney and going out.

B. **Summary and Recommendations**:

Summary of Family/Child Concerns, Priorities, and Resources:
Ms. Dusaban did not express any specific concerns at this time in regards to her daughter's development. Charilyn is currently functioning within normal limits in all areas of development tested today. It appears as if she is being provided with the appropriate stimulation needed to encourage her development.

**Therefore, it is recommended that:**

1. Charilyn's development continue to be monitored as part of the PEDS/GMH follow up program. Her next scheduled evaluation will be in January, 1995, when she is approximately three years old. **The mother will be contacted for an appointment at that time.
2. Charilyn's family continue to encourage her development in all areas. Some suggested activities and developmental guidelines were given to the mother today.

Susan Hokanson

Susan D. Hokanson, M.Ed.
Early Childhood Specialist

Sandra Leon

Sandra D. Leon
Early Childhood Specialist

cc: Parent

# WHERE AMERICA'S SPECIAL BABIES BEGIN

*June W. Holstrum*

*Guam Memorial Hospital (GMH) has a Neonatal Intensive Care Unit (NICU) for infants needing special care at birth. Special care infants are those born with medical problems, such as prematurity, respiratory difficulties, or congenital anomalies. The Guam NICU is similar to special care nurseries on the mainland but lacks some of the sophisticated equipment and medical specialists usually associated with mainland NICUs.*

*The purpose of this study is to describe the developmental outcome of Guam's special care infants and to compare their developmental status to the mainland infants. Babies in this study were admitted to the GMH special care nursery between October 1, 1990, and February 29, 1992. Follow-up developmental evaluations were scheduled for these high-risk infants at the age of 4 and 9 months. Developmental status was described in terms of a) number of infants born with established risk, b) mental and psychomotor developmental quotients, and c) percentage of infants referred to infant/toddler early intervention programs. Included in this study were 100 infants who returned for their first evaluation and 58 infants who returned for their second evaluation.*

*Preliminary findings suggest that the smallest and sickest premature infants on Guam may have a higher mortality and morbidity rate than same size infants on the mainland.*

## INTRODUCTION

Guam, an American Territory, is a small island in the Western Pacific, approximately 3,300 miles southwest of Hawaii. It is the first American soil west of the international date line; where America's day begins. Hence, it is where America's special babies begin. The population of Guam is approximately 133,000 including 21,654 military personnel and their dependents (U.S. Census Bureau, 1990). Approximately 2,600 infants are born at Guam Memorial Hospital (GMH) each year. In addition, 850 infants are born at the Navy Regional Medical Center (Guam Department of Public Health and Social Service, 1990-1992).

Although there have been many follow-up studies of special care infants who were admitted to Neonatal Intensive Care Unit (NICU) in the U.S., there have been none on Guam. Infants included in this report were admitted to Guam Memorial Hospital NICU and Special Care Nursery. Data were gathered on all special care infants born at GMH by Pediatric Evaluation and Developmental Services (PEDS).

The Guam NICU is similar to special care nurseries on the mainland but lacks some of the equipment and medical specialists usually associated with other NICUs. For example, no pediatricians are based in the Special Care Nurseries and there is only one pediatrician with a neonatal specialization. There are no sub-specialists such as pediatric neurologists, cardiologists, or surgeons. The turn over rate of the nursery nurses is high and there are no neonatal clinical nurse specialists. There is

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***June W. Holstrum** is a Behaviorial Scientist at the Center for Disease Control in Atlanta, Georgia. She has a Ph.D., and Ed.S., and an M.Ed. from University of Florida, and a B.A. from the University of Iowa. She may be contacted at the Centers for Disease Control; 4470 Buford Hwy., N.E.; MS/F-15, Chamblee 101; Atlanta, Georgia, 30341-3274.*

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## S BEGIN

*ICU) for infants needing*
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*trol in Atlanta, Georgia.*
*B.A. from the University*
*ford Hwy., N.E.; MS/F-*

a dearth of allied health professionals such as physical and occupational therapists, nutritionists, and social workers to work with the infants and their families. In addition, there is a lack of sophisticated diagnostic equipment, capabilities, and lab facilities. The system of health care for special infants on Guam leads us to hypothesize that the developmental outcome for Guam NICU babies may differ significantly from those of the mainland.

In October 1990, a developmental follow-up program of high risk infants at GMH was initiated by Pediatric Evaluation and Guam Developmental Services. PEDS is located on the University of Guam campus. It is jointly sponsored by the University of Guam, the Guam Department of Education, and the Guam Department of Public Health and Social Services (GDPHSS). The primary purpose of the PEDS/GMH program is to identify infants who are at risk for developmental delays and could benefit from early intervention services. The secondary purpose is to provide information on the developmental outcome of Guam's special babies to the physicians and nurses caring for them. Infants are selected for the follow-up program who have one or more of the neonatal complications listed on the Risk Register (see Figure 1). Infants in this report were part of this on-going follow-up program of GMH special babies.

The purpose of this study is a) to report incidence of children born with established risk and b) to describe the developmental status of at-risk infants at four and nine months of age. The clinical significance of this information is discussed.

## METHOD

All infants born between October 1, 1990, and February 29, 1992, that met the Risk Register criteria were included in this report. Before each infant was discharged from the hospital, his/her medical records were reviewed, the risk register completed, and developmental screening administered by a PEDS staff member. If the mother or other family member was not present during the developmental evaluation, a PEDS staff member met with the family to discuss the results of the evaluation, explain the follow-up program, and obtain an informed consent to participate in the program.

Home visits were made two weeks after discharge. Mothers were interviewed and information updated. The scope and procedures of the follow-up program were reviewed. Concerns, priorities, and resources of the family were also discussed. A developmental screening was completed on each infant.

Follow-up developmental evaluations were scheduled at the PEDS Center for each infant when he/she was at 4 and 9 months. The evaluation was multidisciplinary and included a hearing evaluation, developmental evaluation, parent interview, and behavioral observation. The concerns, priorities, and resources of the family were reviewed. Interviews and questionnaires concerning the health and behavior of the infant were completed. The Mental and Psychomotor sub-scale of the Bayley Scales of Infant Development (Bayley, 1969) were used as a measure of developmental status. The Bayley Scales are designed to assess the developmental

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## Figure 1

**Risk Register**

Subj.#.____ Name:____________________ HOSP.#____________ D.O.B.________

GA(LMP)________GA(ASSES)________SEX_____RACE________________GMH NRMC

APGARS: 1___ 5___ 10___ B.W.___G/___# LENGTH cc/___"H.C. cc/___"

PLURALITY:___Singleton___Twin___Triplet___>3 DELIVERY: SVD IVD C/S XC/S F

PRESENTATION: ___Vertex ___Breech ___Other DAYS ON RESPIRATOR:____________

Mother's Age:____

---

**Parental/Family Conditions**

- ___ Maternal age <18 >35
- ___ Maternal PKU
- ___ Mother HIV positive
- ___ Maternal use of anticonvulsant, antineoplastic or anticoagulant drugs
- ___ Parental blindness
- ___ Parental substance abuse
- ___ Parental mental retardation
- ___ Parental mental illness
- ___ Difficulty in parental/infant bonding
- ___ Difficulty in providing basic parenting
- ___ Lack of stable housing
- ___ Family history of childhood deafness
- ___ No prenatal care

TOTAL P/F CONDITIONS ____________

**Neonatal Complications**

- ___ <1000 gms
- ___ <1500 gms
- ___ <2000 gms
- ___ Resuscitation at birth
- ___ Mechanical ventilation >6 hours
- ___ Required oxygen >7 days
- ___ SGA <10%; LGA <90%
- ___ Head Circumference <10% >90%
- ___ 5 min. Apgar less than 6
- ___ Hypoglycemia: <40 mg% >38 wks
  <30 mg% <38 wks
- ___ Hypocalcemia: <7.5 mg
- ___ Hyperbilirubinemia: >20
- ___ Seizures
- ___ Suspected hearing impairment
- ___ Suspected vision impairment
- ___ Meconium Aspiration
- ___ Infant of diabetic
- ___ Suspected IVH
- ___ Extreme hypo/hypertonia
- ___ Hydrocephalus
- ___ Exchange Transfusion
- ___ Congenital Anomalies ____
- ___ Chromosomal Defect
- ___ Cardiac Disorder/Anomalies

____________________

- ___ Neonatal Infection
- ___ Feeding Problem
- ___ Persistent lethargy >72 hours
- ___ Multiple apneic episodes
- ___ oral-facial anomalies

TOTAL NEONATAL COMPLICATIONS ____________

PEDS Contact __ 1 = Yes 2 = No

Results of NDSS:

- _____ Habituation
- _____ Attention/Interaction
- _____ Motor
- _____ Physiological Systems
- _____ Abnormal Movements
- _____ Reflexes

Primary Care Physician

Clinic

Discharge Date:______________

Age at discharge__________days

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TOTAL NDSS SCORE________

).O.B.________

____ GMH NRMC

C.__cc/____"

VD C/S XC/S F

)R:____________

:ions

ected IVH
ema hypo/hypertonia
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istent lethargy >72 hours
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-facial anomalies

NEONATAL
ICATIONS __________

ntact __ 1 = Yes 2 = No

Physician

—

ays

level of children from 2 to 30 months. Before leaving the PEDS Center, suggestions and brochures on activities and exercises to facilitate development were provided.

### Subjects

Between October 1, 1990, and February 29, 1992, approximately 3,900 infants were born at GMH (GDPHSS, 1990-1992). Of these infants, 250 (6.4%) had at least one of the neonatal complications listed on the risk register and were enrolled in the follow-up program (GDPHSS, 1990-1992). Many infants could not be followed-up due to death, relocation, missed appointments, disconnected phones, or incorrect addresses. Where possible, help was requested from Public Health in tracking down these babies.

*Ethnic Groups*. Ethnic groups of babies in the follow-up are similar to that of the total population. Percentages in each ethnic group are listed in Table 1 for the general population, for infants enrolled in the program, and for infants returning for follow-up evaluations. The low percentage of high-risk Caucasian infants is somewhat misleading. The percentage for the total Guam population includes military and civilian, whereas only civilian babies are born at GMH. The percentage of civilian Caucasians from the 1990 census was unavailable. It appeared that Micronesian babies were over-represented in the high risk population. However, the Micronesian population on Guam may be much larger than reported in the latest census.

**Table 1**
**Ethnic Groups**

High-Risk Infants
Oct. 1, 1990 - February 29, 1992

| | General Population (1990 Census) N=133,152 | High Risk Infants Born at GMH N=250/3,900 | Returned for 4-Mon. Evaluation (N=100) | Returned for 9-Mon. Evaluation (N=58) |
|---|---|---|---|---|
| Chamorro | 43% | 37% | 43% | 46% |
| Filipino | 23% | 20% | 20% | 14% |
| Caucasian | 14% | 1% | 0% | 2% |
| Asian | 7% | 2% | 0% | 0% |
| Micronesian | 2% | 17% | 10% | 11% |
| Mixed | 11% | 23% | 27% | 27% |

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*Marital Status of the Mother.* In the United States, 25.7 % of the babies were born to unwed mothers in 1988 (Rosenbaum, Layton, & Liu, 1991). For Guam, 34.8 % of mothers giving birth were not married (GDPHSS, 1990-1992). Of all the infants brought to PEDS for a follow-up evaluation, 52.8 % were from unwed mothers.

*Infants with Established Risk.* Preliminary data on the incidence of infants born with established risk was collected. Established risk is defined as having a condition that is known to be associated with developmental delay or disability, such as Down's Syndrome or inborn errors of metabolism.

Due to the small number of infants born during this reporting period, incidence rates cannot be established. Table 2 lists the number of children born with conditions known to be associated with developmental problems. Where available, an incidence rate is included.

The data suggest that the incidence of cleft lip and cleft palate (CL/CP) may be higher on Guam than in the U.S. mainland. Approximately 1/390 infants on Guam were born with CL/CP. The mainland rate was 1/550 for whites and 1/2,500 for blacks (Blackman, 1983). The incidence of Down's Syndrome may be lower. Only three Down's Syndrome infants were born during the reporting period on Guam. This represents a Guam incidence rate of 1/1300. Down's Syndrome reportedly occurs 1 in 600 to 800 live births in the mainland (Blackman, 1983). Due to poor diagnostic capacity, only the most severe cardiac anomalies are diagnosed in the neonatal period. Most likely there are considerably more cardiac anomalies than the nine reported.

According to the GDPHSS (1989), the diabetes associated mortality rate is five times higher on Guam than on the U.S. mainland. Data are not available as to the total number of infants born to diabetic mothers. However, 20 infants of diabetics had neonatal complications.

Perhaps the most unusual incident of established risk was the birth of two infants diagnosed as having Pierre Robin Syndrome. Reported incidence rate is 1/30,000 in the mainland (Bergsma, 1973). Major characteristics associated with this syndrome include small chin, cleft palate, respiratory distress, and mental retardation.

Due to lack of diagnostic capabilities, there were some undiagnosed children who may have a chromosomal, genetic, or other type of syndrome. Six children were seen who had severe developmental delays and atypical appearance with unknown etiology.

*Low Birth Weight.* The neonatal mortality rate for low birth weight infants in the United States has significantly decreased since the arrival of Neonatal Intensive Care in the 1960s (Kitchen et al., 1987). Low birth weight is defined as a birth weight of 2500 grams (5 1/2 lbs.) or less. However, low birth weight babies are still at risk for developmental problems (Lipper, Ross, Auld, & Glassman, 1990; Saigal, Szatmari, Rosenbaum, Campbell, & King, 1991) The incidence of low birth weight in the States was 6.9% (Rosenbaum, et al, 1991); for Guam, 7.8% (GDPHSS, 1990-1992). Low birth weight accounted for 59.6 % of the infants enrolled in the follow-

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| Condition |
|---|
| Cleft/Lip<br>and/or<br>Cleft/Palat |
| Down's<br>Syndrome |
| Myelo-<br>meningocei |
| Deformities<br>Extremeties |
| Albino |
| Cardiac<br>Anomalies<br>diagnosed<br>neonatally |
| Infant of<br>Diabetic |
| Achondrop<br>(Dwarfism) |
| Gastro. Inte<br>deformities |
| Pierre Robir |
| Unknown |

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### Table 2
### Incidence of Babies Born with Established Risk
(Oct. 1, 1990 - Feb. 29, 1992;N=3,900)

| Condition | # of GMH Babies | Estimated Incidence | Recorded Incidence |
|---|---|---|---|
| Cleft/Lip and/or Cleft/Palate | 10 | 1/390 | Caucasians=1/550<br>Blacks=1/2,500 |
| Down's Syndrome | 3 | 1/1300 | 1/800 - 1/1000 |
| Myelo-meningocele | 2 | 1/1950 | 1/500 - 1/1000 |
| Deformities of Extremeties | 5 |  | 1 fused hand<br>2 club feet<br>1 extra toe<br>1 ambi bd syn |
| Albino | 1 |  | Caucasian=1/4,000<br>Black=1/15,000 |
| Cardiac Anomalies diagnosed neonatally | 9 | 1/433 | 1/125 Only very severe |
| Infant of Diabetic | 20 | 5% | 2.8% of all pregnancies* |
| Achondroplasia (Dwarfism) | 1 |  | 1/10,000 |
| Gastro. Intes. deformities | 2 |  |  |
| Pierre Robin | 2 | 1/1950 | 1/30,000 |
| Unknown | 6 |  |  |

*Mortality for diabetes nearly 5 time higher in Guam than U.S.

up program; 55 % of the infants who returned for their first evaluation; and 64 % of those who returned for the second evaluation.

There has been a great deal of discussion as to whether it is preferable to use adjusted or unadjusted scores in reporting developmental status. Adjusted scores are calculated by using the infant's age after it is "adjusted" for prematurity, i.e., after the number of weeks the infant was premature is subtracted from his chronological age. Clinicians who take a maturational view support the use of adjusting for prematurity (Ungerer & Sigman, 1983). Those who take an environmentalist viewpoint, suggest that the unadjusted age is more predictive of later development (Miller, Dubowitz, & Palmer, 1984). In an attempt to determine the clinical significance of the test results, the adjusted and unadjusted scores were calculated for each infant.

## RESULTS

### *Survival Rates*

During our reporting period, data was obtained for only 11 babies weighing < 1000 grams (2 lbs, 3 oz.); Five (46%) of these survived. Hack, et al. (1991) reported a survival rate of 66% for infants weighing from 750 to 1000 grams, delivered at the participating centers of the National Institute of Child Health and Human Development of Neonatal Intensive Care Network (NICN). No babies weighing less than 751 grams at birth survived at GMH during the reporting period. The estimated NICN survival rate on the mainland for this lowest weight group was 34%.

### *Descriptive Statistics*

The number of babies returning for their first (4-month) follow-up evaluation totaled 100. They had a mean adjusted age of 3.8 months and mean unadjusted age of 4.7. The mean birth weight was 2496 grams. The babies spent an average of 17.2 days in the hospital.

The number of babies returning for their second follow-up evaluation totaled 58. They had a mean adjusted age of 9.0 months and mean unadjusted age of 10.0 months. The mean birth weight was 2295 grams. The babies spent an average of 18.9 days in the hospital (see Table 3).

### *Follow-up Developmental Status*

The mean Bayley mental developmental quotient (MDQ), adjusted for prematurity, for all infants who returned for the first follow-up evaluation was 97 and the mean adjusted psychomotor developmental quotient (PDQ) was 100. The mean unadjusted Bayley MDQ and PDQ were 82 and 87, respectively. Clearly, the smaller the baby the greater is the impact of adjusting for prematurity. Tables 4 and 5 report adjusted and unadjusted DQs by birth weight for the first evaluation. In the smallest birth weight group the adjusted MDQ was 98 and the unadjusted was 61; a 37-point difference between the adjusted and unadjusted MDQ.

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### Table 3
### Descriptive Statistics for Follow-up Babies

First Follow-up - 4 Months (N=100)

| | MEAN | SD | RANGE |
|---|---|---|---|
| Adjusted Age | 3.8 | 1.7 | 1.5 - 5.7 months |
| Unadjusted Age | 4.7 | 2.0 | 1.6 - 7.2 months |
| Birth weight | 2496 | 792 | 992 - 4479 grams |
| DAYS | 17.2 | 21 | 1 - 85 days |

Second Follow-up - 9 months (N=58)

| | MEAN | SD | RANGE |
|---|---|---|---|
| Adjusted Age | 9.0 | 1.7 | 6.0 - 12.4 months |
| Unadjusted Age | 10.0 | 2.0 | 6.0 - 14.0 months |
| Birth weight | 2295 | 792 | 845 - 4649 grams |
| DAYS | 18.9 | 21 | 2 - 90 days |

### Table 4
### Adjusted Developmental Quotient at First Follow-Up

(Mean Age = 3.8 Months)

| Birth Weight (In Grams) | N (100) | Mean aMDQ | SD | Mean bPDQ | SD |
|---|---|---|---|---|---|
| All Babies | 100 | 97 | 20 | 100 | 20 |
| 1500 or Less | 12 | 98 | 31 | 100 | 20 |
| 1501 to 2000 | 24 | 97 | 20 | 99 | 31 |
| 2001 to 2500 | 19 | 98 | 21 | 102 | 22 |
| 2501 to 3000 | 14 | 100 | 14 | 101 | 17 |
| 3001 TO 4000 | 27 | 94 | 18 | 98 | 14 |
| > 4000 | 4 | 91 | 4 | 103 | 14 |

[a] Bayley Mental Developmental Quotient
[b] Bayley Psychomotor Developmental Quotient

### Table 5
### Unadusted Development Quotient at First Follow-up

(Mean Age = 3.7 Months)

| Birth Weight (In grams) | N (100) | Mean aMDQ | SD | Mean bPDQ | SD |
|---|---|---|---|---|---|
| All Babies | 100 | 82 | 19 | 87 | 19 |
| 1500 or Less | 12 | 61 | 19 | 66 | 17 |
| 1501 to 2000 | 24 | 74 | 15 | 76 | 14 |
| 2001 to 2500 | 19 | 82 | 13 | 87 | 11 |
| 2501 to 3000 | 14 | 93 | 14 | 98 | 16 |
| 3001 to 4000 | 27 | 93 | 19 | 98 | 18 |
| > 4000 | 4 | 92 | 4 | 103 | 14 |

[a] Bayley Mental Developmental Quotient
[b] Bayley Psychomotor Developmental Quotient

Tables 6 and 7 show the test results for the 9-month follow-up evaluations. The mean adjusted MDQ and PDQ for the second follow-up evaluation for all birth weight groups were 99 and 97, respectively. The unadjusted MDQ and PDQ were 89 and 88, respectively. The scores were surprisingly consistent from the first to the second evaluations. The question of which scores are more predictive for this population remains to be answered through later evaluations.

In the smallest birth weight group, the adjusted MDQ was 83 and the unadjusted MDQ was 64. The difference between the means of the adjusted and unadjusted scores for infants weighing less than 1500 grams was only 19 points at the second evaluation. As the babies get older, the correction for prematurity should continue to make less of a difference. Perhaps at 4 months, adjusting for prematurity overcompensates and yields unrealistically high scores. The numbers hint that perhaps the unadjusted scores might be more predictive, but the data set is too small and the infants still too young to make such conclusions at this time.

*Eligibility for Special Education*. As was mentioned at the beginning of this report, one of the primary reasons to follow these special babies is to determine which ones can benefit from early intervention services. After each evaluation, the assessment team, including the parents, decide if the infant and family would benefit from a referral to the early intervention program.

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Determinations for early intervention program eligibility were made for a total of 141 infants. Of these infants, 42 (30%) were referred to special education. Twenty-three percent of the eligible infants were referred due to developmental delay and 7% were referred as at risk for developmental delay (see Table 8). The at-risk infants were developmentally within normal limits at the time of assessment. However, they were at risk for delay due to environmental or biological factors, e.g., parents were mentally handicapped, history of child abuse, siblings in special education, cleft-lip or cleft-palate. The 99 infants not eligible for special education remained on a monitoring schedule.

### Table 6
### Adjusted Development Quotients at Second Follow-up
(Mean Age = 9.1)

| Birth Weight (In grams) | N (58) | Mean $^{a}$MDQ | SD | Mean $^{b}$PDQ | SD |
|---|---|---|---|---|---|
| All Babies | 58 | 99 | 20 | 97 | 21 |
| 1500 or Less | 8 | 83 | 24 | 85 | 30 |
| 1500 to 2000 | 16 | 103 | 18 | 99 | 18 |
| 2001 to 2500 | 13 | 99 | 20 | 99 | 20 |
| 2501 to 3000 | 9 | 99 | 18 | 96 | 16 |
| 3001 to 4000 | 11 | 104 | 21 | 101 | 24 |
| > 4000 | 1 | 117 | 0 | 119 | 0 |

$^{a}$Bayley Mental Developmental Quotient
$^{b}$Bayley Psychomotor Developmental Quotient

### Table 7
### Unadjusted Developmental Quotients at Second Follow-up

(Mean Age = 10.0)

| Birth Weight (In grams) | N (58) | Mean aMDQ | SD | Mean bPDQ | SD |
|---|---|---|---|---|---|
| All Babies | 58 | 89 | 21 | 88 | 20 |
| 1500 or Less | 8 | 64 | 12 | 68 | 16 |
| 1502 TO 2000 | 16 | 86 | 16 | 85 | 15 |
| 2001 TO 2500 | 13 | 90 | 17 | 91 | 16 |
| 2501 TO 3000 | 9 | 94 | 20 | 92 | 14 |
| 3001 TO 4000 | 11 | 102 | 21 | 99 | 25 |
| > 4000 | 1 | 117 | 0 | 119 | 0 |

[a] Bayley Mental Developmental Quotient
[b] Bayley Psychomotor Developmental Quotient

### Table 8
### Eligibility Status of Follow-up Infants

(N=141)

| | | |
|---|---|---|
| Developmentally Delayed | 32 | 23%* |
| At Risk | 10 | 7%* |
| Monitoring Program | 99 | 70% |

* Referred to Special Education

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## DISCUSSION

Obviously this report includes only preliminary data. The sample is too small to draw conclusions regarding incidence rates or whether infants treated at Guam's NICU have a higher morbidity rate than their age mates on the mainland. At this point it is difficult to make comparisons between Guam and U.S. data. However, preliminary results do indicate that our smallest, sickest babies may have a higher mortality and morbidity rate than mainland babies.

### *Implications and Recommendations*

One of the motivating forces for implementing the follow-up program was to identify special needs' infants. The program requires repeated evaluations by several professionals. Questions that have been asked are, "Is the hospital follow-up program effective in identifying special needs infants?" and "Is it cost effective?" In the first 17 months of the program, 42 of the follow-up program babies were identified as special needs' infants and were enrolled in the infant and toddler intervention program. This represents 66% of all infants in the same age range referred to intervention program during the same time period. Other infants were referred to PEDS from physicians, clinics, relatives, Public Health, and the Department of Education. A few of the 42 infants identified by the follow-up program would have been referred to an early intervention program without the help of the hospital follow-up. However, most likely the majority would not have had the benefit of early intervention until they were older. The early identification of special needs' infants has already had a significant impact on the growth of the infant and toddler intervention program. It is expected as the program continues and more babies are identified, that the need for professionals trained to work with infants and toddlers will increase. The increase in infants enrolled in early intervention programs and the increase in professionals working with them will require an increased amount of dollars allocated for early intervention. However, research clearly demonstrates that quality early intervention programs not only improve the developmental and behavioral status of children but are also cost effective (Infant Health and Developmental Program, 1990; Martin, Ramey, & Ramey, 1990; Resnick, Eyler, Nelson, Eitzman, & Bucciarelli, 1987; Smith & Strain, 1988).

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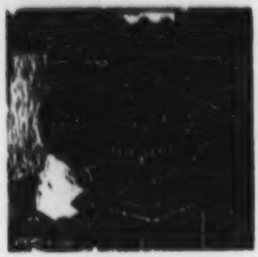
Volume 3, 1992

# MICRONESIAN EDUCATOR

A Journal of Research and Practice about Education
in Guam and the Micronesian Region

A Publication of the College of Education University of Guam

## What is the Infant Toddler Early Intervention Program?



### *The Vision*

The Infant Toddler Early Intervention Program is committed to providing family-centered early intervention services to children birth to three years of age who have disabilities or who are at high risk of having substantial developmental delays.

***Components of the Program***

- Guam Interagency Coordinating Council (GICC)
- Pediatric Evaluation and Developmental Services (PEDs)
- Infant Toddler Program
- Toddler Transition Center

## Who Would Need Early Intervention Services?

- A child with a developmental delay or a disability.
- A child whose: hearing,
  thinking,
  seeing,
  talking,
  playing and/or
  moving
  are different from others of the same age.

## What Types of Services are Available to Families?

Children identified as having a disability and are in need of special education services have a right to services.

These services are provided to help your child grow and develop and to help you care for your child.

**Such services are, but not limited to:**

- Evaluation Services (includes hearing and vision screening)
- Speech Therapy
- Physical and/or Occupational Therapy
- Home visits
- Linkage to other Community Services
- Family Counseling

For more information, please call the Division of Special Education, Infant Toddler Program at 475-0547/63

## Developmental Stages

***Here are examples of what most children birth to 3 years of age are expected do:***

### *3* Months of Age

- Grasps toys or hair
- Smiles
- Recognizes bottle or breast
- Makes cooing sounds
- Lifts head and chest when on stomach

### *6* Months of Age

- Reaches for objects and picks them up
- Recognizes familiar faces
- Follows moving objects with their eyes
- Babbles
- Helps hold the bottle during feeding

### *12* Months of Age

- Sits without support
- Plays peek-a-boo or patty cake
- Waves bye-bye
- Knows five or six words
- Drinks from a cup

### *2* Years of Age

- Feeds self with a spoon
- Shows affection
- Identifies hair, eyes, ears, and nose by pointing
- Uses two-to-three-word sentences
- Plays independently

### *3* Years of Age

- Walks up steps
- Plays with other children for a few minutes
- Repeats common rhymes
- Uses three-to-five word sentences
- Toilet trained

Guam Department of Education
Division of Special Education
Infant & Toddler Early Intervention Services
P.O. Box DE
Agana, Guam 96910
Phone: (671) 475-0547/63
FAX Phone: (671) 475-0567

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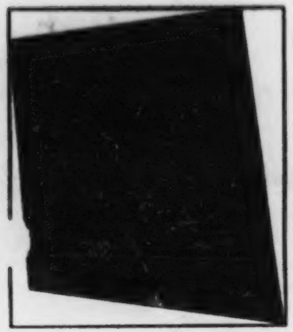
# *Infant & Toddler Early Intervention Services*

## *For Families with Infants and Toddlers with Special Needs*

***Services Coordinated by***
**Guam Department of Education**
***Division of Special Education***
**PART H Program**

## What is the Pediatric Evaluation and Developmental Services (PEDS)?



Through collaborative interagency coordination, Pediatric Evaluation and Developmental Services (PEDS) provides screening, assessment, referrals and initial information/intervention for children birth to 3 years of age with or at risk for developmental delays/disabilities and their families.

*What types of services are available for my child?*

- Newborn Developmental Assessment
- Developmental Assessment
- Speech Language Evaluations
- Physical Therapy Evaluations
- Audiological (Hearing) Evaluations
- Referral for further Support Services
- Education and Development on Early Childhood Issues

## When should my child be tested?

Referrals to PEDS may come from parents, relatives, friends and health professionals (i.e., nurses, physicians, health counselor, etc.), who have concerns about the overall development of a child. For a better idea of what to look for, we've provided you with a list of "questions" in this brochure.

PEDS also has a **"Monitoring" Program**. This program provides Free periodic developmental evaluations to babies who had spent some time in the Neonatal Intensive Care (NICU) nursery at the hospital after delivery. This monitoring program will assist you keep track of your baby's progress after he/she has been discharged from the hospital. So, if your baby was in the NICU, and if you are interested in this program, call PEDS and ask to speak to our nurse or the developmental evaluator.

## Questions to ask yourself about the development of your child.

- ☐ Does your child catch colds often?
- ☐ Does he/she pull at his/her ear a lot?
- ☐ Is there an unpleasant smell from his/her ears?
- ☐ Has he/she had many ear infections or other ear problems?
- ☐ Does your child startle or jump when he/she hears a loud sound?
- ☐ Does your child seem too stiff or too weak?
- ☐ Does your child have unusual (different, clumsy or uneven) movements?
- ☐ Does your 1- to 2- year -old still just continues to cry and /or points to let you know what he/she needs or wants?
- ☐ Does your child have difficulty reaching for and holding on to objects?

**If your answer is "yes" to any of the questions above, please call PEDS. Our hours are from 8:00 a.m. to 5:00 p.m. Monday through Friday except Holidays. A staff will respond to your concerns. If needed, an appointment for specific and appropriate evaluation(s) will be arranged for your child at no cost. Please call 735-2455/6.**

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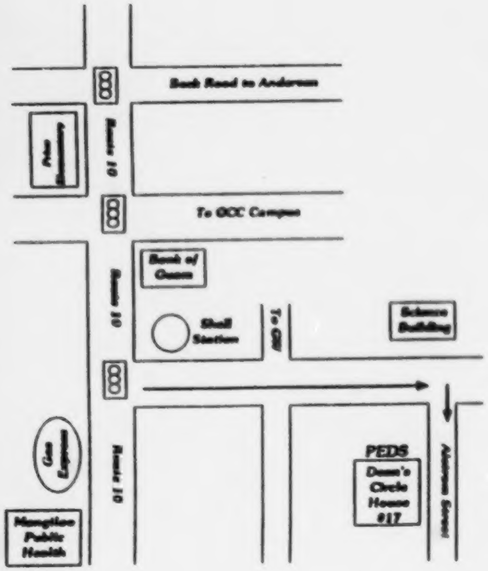
## Map to PEDS



Pediatric Evaluation and Developmental Services
University Affiliated Program
Hse. #17 Dean Circle
UOG Station
Mangilao, Guam 96923
Phone: 735-2455/6
FAX: 734-7820

# Pediatric Evaluation and Developmental Services (PEDS)

DPHSS — UOG — DOE

Administered by the ***University Affiliated Program*** **with support from the** ***Department of Education, Department of Public Health and Social Services, Guam Memorial Hospital and the University of Guam***

Technical Report Proposal:

# The Self Study Evaluation of the Guam Pediatric Evaluation and Developmental Services (PEDS) Unit

## General Scope of the Evaluation

*(Micronesian palm frond baby basket)*

Velma A. Sablan
Self Study Team Manager
Contracted Under Guam University Affiliated Programs
May, 1996

Proposal delivered
to GICC — of
May, 1996

Technical Report

# THE PEDIATRIC EVALUATION AND DEVELOPMENTAL SERVICES (PEDS)

## PRELIMINARY TECHNICAL REPORT
## SELF STUDY EVALUATION PROPOSAL PLAN

*by*

***Velma A. Sablan***
***Self Study Team Manager***

## AUTHORIZATION:

The evaluation of the PEDS unit was recommended by the Guam Interagency Coordinating council (GICC) and authorized by the Guam Department of Education, the designated lead agency for the Part H program. Under a subcontract to the Guam University Affiliated Program (Guam UAP), the PEDS evaluation was included as an activity under the subcontract. This evaluation is the first stage of program planning for a key program serving the birth to 3 population in Guam.

## WHAT IS PEDS?

PEDS is a interagency collaborative unit that serves children between the ages of birth to 3 years and their families. These children have been identified as children with disabilities or are at risk for developing a disability due to biological or environmental factors. PEDS is housed at the University of Guam, Dean's Circle, House #18. A staff of seven compose the core of the PEDS unit. Funding for the PEDS unit comes primarily from a tri-agency agreement between the Department of Education, the lead agency for Part H programs, the University of Guam, and the Department of Public Health and Social Services.

The PEDS unit has been in existence since August, 1989 and was created under a Memorandum of Understanding between the three agencies. This MOU has been renewed every three years. When the existing MOU expired, the need for the continuation of the unit became increasingly apparent, however the extent of services and other issues required more agency input and an extension of 6 months was approved by all the agencies in order to more carefully structure the direction and mission of the PEDS Unit. An Ad Hoc Committee was organized so that a third PEDS MOU could reflect the scope of services provided by the PEDS unit, as the need for the unit within the Guam community expanded significantly while the staffing pattern and fiscal resources remained little more than constant.

An Ad Hoc Committee for PEDS was created for the primary purpose of developing a new 5 year MOU that will expand the agencies and services represented, i.e. Guam

Memorial Hospital and the Department of Mental Health. The process is being facilitated by a subcontract to Guam University Affiliated Programs for the Early Intervention initiative area.

It is anticipated that the new MOU will reflect the involvement of each of the collaborating units and will provide direction for it's future. This evaluation is designed to assist in the decision making process and to provide both the lead agency, the Guam DOE and the GICC with an update on services provided to families with children with disabilities or at risk who are between birth to three years, being served by the PEDS unit.

This evaluation was recommended by the Guam Interagency Coordinating Council to evaluate the need for the PEDS unit and for the development of a program evaluation instrument for continued assessment of the effectiveness and viability of the PEDS unit.

## APPROACH TO THE PEDS SELF-STUDY:

The final evaluation report will follow the elements recommended by the Part H Self Study Instrument, Version 1.2, published by the Office of Special Education Programs, U.S. Department of Education, January, 1994. This publication, while targeted to all Part H activities, will be adapted for the PEDS evaluation, retaining critical aspects of the evaluation process delineated by the Part H Self Study Instrument. The publication recommends that a self study team comprised of a group of individuals such as professionals, consumers, and other interested persons with a local perspective who have a stake in the early intervention system and the interest of young children and their families, be included in the self study team.

Although the concept of "self study" demands that those individuals who are directly involved in PEDS initiate and conduct the evaluation process, the approach taken here will be the use of an evaluator who will act as the "Manager," as recommended by the Part H Self Study Instrument, who will gather data from multiple sources, summarizing and interpreting the findings in collaboration with the PEDS staff so that the element of "self study" is maintained with the Manager supporting the process through recording keeping and feedback. This approach is necessary due to the multiple agencies who are directly or indirectly involved in the PEDS operation.

The intent of this initial evaluation will be to enhance the self evaluation process within the PEDS unit so that the self study process will be adopted as an ongoing activity within the unit.

Steps in the PEDS Evaluation Process:

The Part H Self Study Instrument, Version 1.2 recommends an eight (8) step procedure for completing the self-study.

1. Select a Manager of the Self-Study-

This task has been completed and has been assigned to Velma A. Sablan, Project Evaluator. This person, according to the Part H Self Study Instrument, Version 1.2 must be "an individual who is very knowledgeable about the early intervention system at the State and local levels and possesses a basic understanding of self-study or other types of evaluation." (pg. I-6) Velma A. Sablan has been a faculty member at the College of Education, Special Education Program since 1983 and taught in the Special Education Early Intervention graduate program. She was a consultant with Head Start when it was first initiated in Guam in 1973 and also worked the Guam Community College in the Child Development (CDA) program. She was one the team members who helped structure the first PEDS MOU that established the unit under Part H. She recently completed a Ph.D. in Educational Research and Program Evaluation, in a program that contained a 15 hour block of courses in multicultural education.

2. Introduce the Self Study Concept to participants

Through meetings with the PEDS staff, the GICC, the PEDS Ad Hoc Committee, the Guam UAP, and other key stakeholders, the self study process was explained and described in terms of its purpose, underlying principles, importance, and potential to facilitate PEDS program improvement and linkages to other program review components. This process will continue to take place, keeping participants informed of the self study concept and its usefulness. Since any evaluation process tends to be threatening, opportunities to discuss concerns about the process will be made available as often as possible. Every effort will be made to focus on identified accomplishments and areas needing improvement.

3. Identify key tasks

Because of the interagency collaborative support that forms the basis of the PEDS unit, the task of data collection will come from key data sources and participants including:

a. Meetings with the PEDS staff, both as a group and individual interviews with each PEDS staff member

b. Review PEDS MOUs and Annual Reports

c. Records and files on the PEDS site

d. Meeting minutes from GICC where PEDS activities are referenced

e. Meeting minutes from the PEDS Ad Hoc Committee at their monthly meeting

f. Input from the Part H Coordinator, Guam DOE

g. Input from the Guam UAP Early Intervention Initiative Area Coordinator

h. Input from the Director, Guam UAP

i. Recommendations made by Dr. Allen C. Crocker, M.D., Guam UAP consultant who made a site visit to PEDS in October, 1995

j. Special Education Program Coordinator, College of Education, UOG

k. Interviews with Families who have received or are currently being served by the PEDS unit

l. Site Observations of PEDS service delivery

m. Vital statistics on births from the Department of Public Health

n. Other data sources to be identified as the evaluation process proceeds

4. Assign persons responsible to conduct tasks

Four key individuals will assist in providing support to self study tasks. This includes: Dr. Margaret Blaz, Acting Director of the PEDS unit, Elaine Eclavea, Early Intervention Initiative Area Coordinator for the Guam UAP, Terry Fejerang, Policy Planning and Program Development Initiative Area Coordinator for the Guam UAP, and Leilani Nishimura, Part H Coordinator for the Guam UAP.

5. Collect information

As recommended by the Part H Self Study Instrument, Version 1.2 the self study will try as much as possible to base findings on information and data that can be documented or are measurable. This includes such items as:

- written policies and procedures
- meeting minutes and agendas
- inservice training materials
- IFSPs
- information tracking systems (i.e. child counts)
- funding data
- parent letters and interviews
- survey data

6. Analyze and interpret the information

Once all data has been collected, the final analysis and interpretation of the findings will be coordinated by the Manager and a final self study report of the PEDS unit will be generated distributed to the appropriate individuals and agencies.

7. Plan for improvement and implement needed changes

The follow up procedure that will be planned within the PEDS Self Study will include a method of determining actions that are designated as high priority. Actions across topics will be structured for a "Comprehensive One Year Plan of Action" as recommended by Part H Self Study Instrument, Version 1.2 and in conjunction with the new 5-year MOU being developed by the Ad Hoc Committee. Goals, accountable agencies, funding sources, dates and timelines will be built into the plan for improvement which will be mutually developed with agency representatives.

8. Describe the process used in conducting the self study

The Part H Self Study Instrument, Version 1.2 recommends that the process used to conduct the self study be captured so that the process is ongoing within the unit and needed changes are anticipated and can be assigned priority.

## BENEFITS OF THE PEDS SELF STUDY:

The PEDS unit has been in existence and operational on the UOG campus for some seven (7) years. Although annual reports have been generated, a comprehensive assessment of the PEDS unit from a multi-agency perspective has only now been initiated. As the growth and expansion of the PEDS unit has continued, the evaluation activity will result in an increased knowledge about the State system for serving infants and toddlers. It will increase an awareness and motivation to solve problems and improve both the PEDS unit and the State system.

Although the PEDS unit has been operational for some years, the history of the development of PEDS is contained in several documents and no single report exits which documents the establishment and purposes of the PEDS unit over the seven year period. The final evaluation will document these historical beginnings.

## CONFIRMATION OF FINDINGS

To guard against problems that could affect validity of findings and to evaluate the PEDS unit objectively, participants will be asked to give input impartially and not with personal self interest, avoiding issues of protectionism or concealment of problems and deficits in the PEDS unit. In keeping with the recommended method by the Part H Self Study Instrument, Version 1.2, judgments made by data sources will be validated by consumers and providers who possess different experiences and perspectives of the PEDS unit.

## ACTIVITY TO DATE:

### PEDS STAFF

On April 12 1996 an extended three hour meeting with the PEDS staff was completed. From this meeting, the following data was gathered:

1. Staffing Pattern-the PEDS team is lacking significant professional members that are in critical need, including a full-time PEDS Director, a Social Worker, and a secretary.

2. Operations-areas of extreme concern were presented on:

   a. Fiscal and Budgetary Support for the unit-the interagency nature of the PEDS unit makes budgetary issues and procedures challenging at best and difficult for future planning.

   b. Physical Plant-the PEDS site has been in violation of IDEA in that the bathrooms, observation rooms, and test rooms are not accessible to wheelchairs

   c. Equipment-computer printers are obsolete or are not functioning making report writing difficult to disseminate and telephone and telephone lines are needed as one line ties up operations and offers no privacy for professionals making sensitive or confidential calls to families.

   d. Continuity of Services for Identified Infants-once identified and screened by PEDS, the staff is unclear if children have been served consistently or if there are areas in which PEDS staff can offer support for families. The lack of some feedback process to monitor progress is needed

e. More Effort to a Team Approach-the need to work more closely with the Guma Nene staff was identified as a critical, particularly proximity to PEDS, collaboration among professionals on IFSPs, and continuity of services.

f. Interdisciplinary Training on Early Intervention-the need to have other programs within the University have an awareness of the PEDS unit in order to conduct further research on the birth to 3 year population, coordinate practicum and observation experiences, and to recruit new professionals to the field of early intervention. The UOG programs targeted are Nursing, Social Work, Education, and Allied Health.

g. Data Management-Currently all data gathering is being done by hand using an intake information sheet. The original automated data system that was developed by the UOG Computer Center, called Informix Data System, crashed and a substantial amount of information was lost. The system was initiated in the Fall, 1990 and it crashed in the Spring, 1995. The PEDS staff found that the system was very repetitive of demographic information which was tedious and unnecessary, it wasn't user friendly, and lacked a manual for first time users and trouble shooting. It was useful for some data but lacking in other areas. The output lacked a legend for explaining various codes. For audiometric data, the need for more parameters and fields are needed because of the larger age group that is seen by the Audiologist at PEDS. The PEDS Staff described the elements of a system that would be required. The need for a good data management system as well as maintenance of computer hardware is a critical need.

h. Communication-telephones are located only in the reception areas and confidential calls are made in public areas. Telephones are needed within offices. A fax machine is also needed to transmit documents across agencies.

i. Consumer and Service Provider Surveys-the need for a parent survey to determine parent satisfaction of PEDS service and to generate consumer reports for service providers was targeted as an essential needs.

j. Transition PEDS-Guma Nene-The timeframe from testing to eligibility is 45 days. Testing is essential before placement to Guam Nene. Testing backlog creates a bottleneck prior to placement and precious time is lost for this age group. Paperwork bogs down the number of children who can be seen. Everybody is doing their own clerical support, when somebody gets ill the cancellations and backlog of both children and reports is staggering.

k. Physical Therapy-space and specialized equipment is needed. There is no privacy for therapy sessions and there is a big issue of sanitation when public areas are used for therapy sessions.

l. No Shows-the no show rates for screening and evaluation is further hampered by the fact that there is no TA to remind patients of appointments.

m. Parent Enticements-the need for a mechanism to get parents more involved with the birth to 3 year children is needed.

n. Cultural Issues-the need for a translator for different languages within Micronesia is needed to improve communication and to get better show rates. There is a need for a roster of speakers of Tagolog and the Micronesian languages.

o. The Developmental Nurse needs a counterpart within both the Naval Hospital and the Guam Memorial Hospital.

p. There is a need for Staff Development opportunities to stay up to date on new techniques with the birth to 3 year population. Conference attendance using both on site and telecommunications was discussed.

q. Interagency collaborations with other agencies to be able to attend workshops funded by other agencies that is pertinent to serving the birth to 3 year population.

r. The need for a consulting M.D. to get medical input on some children with specific medical issues was cited by the staff.

**GICC Meeting**

On April 18, 1996, the Manager attended the GICC meeting to inform the members of the self study evaluation process and to get input from members on aspects of the evaluation that they would like to see included. The following is data gathered from this meeting:

1. Personnel Development-there is a need for the development of Territory wide early intervention competencies for those who serve this population.

2. Recruitment of personnel for early intervention services

[Pediatrician]

3. Is PEDS a good place where families can go for information on normal infant development?

4. How fast does service delivery take place once an infant is identified?

5. Why does there have to be so much paperwork? Why isn't it user friendly?

6. How do individual children do on objective examinations? What have been outcomes? How do parents report in terms of rate of improvement and are they objective?

7. There is need to set up a database

8. How well are children and families being served?

9. What are the needs for other services?

10. How well is the community being served?

[Nursing]

11. What does PEDS do in relation to preventive care, i.e. immunizations?

[Mental Health]

12. Has there been a parent survey of PEDS satisfaction?

13. Of those identified, how many go through the program? Where is breakdown taking place? How can these children get back on track for services? Wnat are barriers?

14. Are we really identifying the number of children based on birth rate on Guam?

## ANTICIPATED OUTCOMES OF THE PEDS SELF STUDY:

In addition to policy planning and future directions, the PEDS evaluation will determine if infants are being served as intended in the Part H application. It will put early intervention stake holders in a better position to determine the viability of PEDS as an interagency unit. It will help to identify PEDS's areas of strength and effectiveness, as well as areas that require further attention or support. It will help develop a relevant Action Plan for the next 5 years. Finally, the PEDS evaluation will give the lead agency, Guam Department of Education, more insight into capacity building for the Part H delivery system.

Velma A. Sablan
Self Study Team Manager

Video Presentation to GICC
Copies to: S. Spencer & L. Nishimura
September 19.1996
PARC Hotel

# The Self Study Evaluation of the Guam Pediatric Evaluation and Developmental Services (PEDS) Unit

## General Scope of the Evaluation

Approach to the PEDS Evaluation as Recommended by the Part H Self Study Instrument:

1. Select a Manager of the Self Study
2. Introduce the Self Study Concept to Participants
3. Identify Key Tasks
4. Assign Persons Responsible to Conduct Key Tasks
5. Collect Information
6. Analyze and Interpret the Information
7. Plan for Improvement and Implement Needed Changes
8. Describe the Process Used in Conducting the Self Study

Presented to
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Several in attenda

# IDENTIFYING KEY TASKS

1. What is the status of the PEDS Staffing Pattern? What are areas of need? Has there been the adequate utilization of all personnel?

2. What is the status of the PEDS operating procedures? What are areas of strength? Are operating procedures clear and understandable? What are needed improvements that need to be made?

3. What is the status of the PEDS Physical Plant? What aspects of the physical plant should remain unchanged? What improvements need to be made?

4. What are PEDS fiscal resources? How has PEDS managed these resources? What are areas of need?

5. Has PEDS provided the service to the Birth to 3 year population that it was designed to serve? What are strengths and weaknesses that have been identified by both families and service providers?

6. Given the findings from above, what is the prioritized plan for improvement to implement needed changes for the PEDS unit?

Data Sources:

Interviews with PEDS Staff
Interviews with the Part H Coordinator
Interviews with the Guam UAP-Early Intervention Initiative Area Coordinator
Input from GICC members
Review of PEDS Annual Reports
Interviews with the former Director of PEDS Unit
Interviews with Parents and extended family members
Interviews with Professionals, i.e. Physicians, Nurses, Other State Directors of 0-3 Programs (State of Hawaii), teachers, social workers, etc.
On-site Observations at GMH, PEDS, & Guma Nene
Review of Public Health Vital Statistics
Review of Publications disseminated by PEDS, i.e. brochures, forms used, degree programs, research articles, etc.
Review of current national publications in Early Intervention, i.e. Zero to Three/National Center for Clinical Infant Programs

**1. What is the status of the PEDS Staffing Pattern? What are areas of need? Has there been the adequate utilization of all personnel?**

Findings: A. There is a 7 member staff supporting PEDS

1. Speech & Language Pathologist - DPH&SS
2. Audiologist -DOE
3. Physical Therapist-DOE
4. Developmental Examiner-DOE
5. Audiometrist-DOE
6. Developmental Nurse-DOE
7. Clerk Typist/Secretary-(newly recruited) DOE

B. The **lack of a Director** for the last 4.5 years has critically impacted PEDS operations. The cross utilization of Dr. Blaz as Speech and Language Pathologist and Acting Director has been less than adequate for policy, planning, and administration of the PEDS unit. This position is critical given the interagency coordination of resources, service, and information among key agencies.
The use of a clincial service provider as a part time administrative head impacts flow of vital information across agencies, public awareness, quality of service, record keeping, day to day needs of the unit, biased view of priorities, and other administrative responsibilities critical to operations.

C. The **need for a Social Worker** to provide services to families and to provide linkage between social service programs and the home was identified as a critical area of need.

D. There is a **need for Second Developmental Nurse** to bridge the connection between GMH, PEDS, and the Lead Agency. The current Developmental Nurse is serving the NICU and Nursery where an average of 300 babies are born each month with an average of 60 babies in the NICU or Intermediate Care Nursery each month requiring follow care and management.

E. The **need for a consulting M.D.** to get medical input on some children with specific medical issues was cited by the staff.

**2. What is the status of the PEDS operating procedures? What are areas of strength? Are operating procedures clear and understandable? What are needed improvements that need to be made?**

Findings:

STRENGTHS:

A. The PEDS staff has managed to maintain operations at a basic functional level through staff cooperation and collaboration. All staff members assist and support one another in intake procedures, sharing equipment, support with scheduling, transportation, etc.

B. There are adopted intake forms, referral procedures, case history forms, and other tracking mechanisms in place that are being regularly used. There is no Operations Manual that is published and updated as needs change, this is most likely due to the lack of an administrative head.

AREAS FOR NEEDED IMPROVEMENTS:

A. Equipment-computer printers are obsolete or are not functioning making report writing difficult to disseminate and telephone and telephone lines are needed as one line ties up operations and offers no privacy for professionals making sensitive or confidential calls to families

B. Continuity of Services for Identified Infants-once identified and screened by PEDS, the staff is unclear if children have been served consistently or if there are areas in which PEDS staff can offer support for families. The lack of some feedback process to monitor progress is needed

C. More Effort to a Team Approach-the needs to work more closely with the Guma Nene staff was identified as a critical area of need, particularly proximity to PEDS, collaboration among professionals on IFSPs, and continuity of services.

D. Interdisciplinary Training on Early Intervention-the need to have other programs within the University have an awareness of the PEDS unit in order to conduct further research on the birth to 3 year population, coordinate practicum and observation experiences, and to recruit new professionals to the field of early intervention. The UOG programs targeted are Nursing, Social Work, Education, and Allied Health.

E. Data Management-Currently all data gathering is being done by hand using an intake information sheet. The original automated data system that was developed by the UOG Computer Center, called Informix Data System, crashed and a substantial amount of information was lost. The system was initiated in the Fall, 1990 and it crashed in the Spring, 1995. The PEDS staff found that the system was very repetitive of demographic information which was tedious and unnecessary, it wasn't user friendly, and lacked a manual for first time users and trouble shooting. It was useful for some data but lacking in other areas. The output lacked a legend for explaining various codes. For audiometric data, the need for more parameters and fields are needed because of the larger age group that is seen by the Audiologist at PEDS. The PEDS Staff described the elements of a system that would be required. The need for a good data management system as well as maintenance of computer hardware is a critical need.

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H. Transition PEDS-Guma Nene-The timeframe from testing to eligibility is 45 days. Testing is essential before placement to Guam Nene. Testing backlog creates a bottleneck prior to placement and precious time is lost for this age group. Paperwork bogs down the number of children who can be seen.

Everybody is doing their own clerical support, when somebody gets ill the cancellations and backlog of both children and reports is staggering.

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K. Cultural Issues-the need for a translator for different languages within Micronesia is needed to improve communication and to get better show rates. There is a need for a roster of speakers of Tagolog and the Micronesian languages.

L. There is a need for Staff Development opportunities to stay up to date on new techniques with the birth to 3 year population. Conference attendance using both on site and telecommunications was discussed.

M. Interagency collaborations with other agencies to be able to attend workshops funded by other agencies that is pertinent to serving the birth to 3 year population.

### 3. What is the status of the PEDS Physical Plant? What aspects of the physical plant should remain unchanged? What improvements need to be made?

A. The "home like" atmosphere of the Dean's Circle house at UOG has contributed positively and significantly to providing services. Many families, especially newly arrived Micronesian families find the present facility warm, welcoming, and they are more comfortable in the home-type context of PEDS.

B. PEDS site has been in violation of Section 504 - bathrooms, observation rooms, and test rooms are not accessible to wheelchairs. GSAT will be doing a complete evaluation of this issue.

C. Physical Therapy-space and specialized equipment is needed. There is no privacy for therapy sessions and there is a big issue of sanitation when public areas are used for therapy sessions.

D. The growing staff coupled with office, equipment and clinical space requires that expansion of the current physcial plant is a critical area of need.

4. What are PEDS fiscal resources? How has PEDS managed these resources? What are areas of need?

The absence of a Director has made the coordination of fiscal resources and provision of services, which Dr. Blaz currently responsible for, an area needing immediate attention. The Part H Coordinator has been providing assistance but the interagency contributions which require continious monitoring is being neglected. Dr. Allen Crocker's observation that PEDS is doing a wide range of activities in the face of limited resources would indicates that PEDS is managing its resources to fullest extent, however the potential for increased cross agency supports, both in kind contributions and budget allocations from Part H, local contributions and private donations are still untapped.

5. Has PEDS provided the service to the Birth to 3 year population that it was designed to serve? What are strengths and weaknesses that have been identified by both families and service providers?

GMH Birth Records from October to July indicate the following averages:

Average number of births per month: 299 x 12 months = 3,588
Average number of births < 2500 grams per month: 19 x 12 months = 228
Average number of birth requiring Intermediate Care per month: 61 x 12 months = 732
Average number of births requiring NICU Care per month: 7 x 12 months = 84
Average number of birth resulting in death per month: 2 x 12 months = 24

Part H Annual Report for 1995-1996 reported that 192 infants were determined eligible for Early Intervention Services. Combined projections for Intermediate Care and NICU Care infants totals 960 potential infants requiring EIS services in any given year. Based on last years counts only 2% are being identified.

6. Given the findings from above, what is the prioritized plan for improvement to implement needed changes for the PEDS unit?

Immediate:

1. Hire a Director for PEDS

2. Development of a 5 year comprehensive plan for PEDS which incorporates the needs of Guam and demonstrates a phase by phase plan for expansion of services.

INPUT:

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D. Interdisciplinary Training on Early Intervention the need to have other programs within the University have an awareness of the PEDS unit in order to conduct further research on the birth to 3 year population, coordinate practicum and observation experiences, and to recruit new professionals to the field of early intervention. The UOG programs targeted are Nursing, Social Work, Education, and Allied Health.

E. Data Management-Currently all data gathering is being done by hand using an intake information sheet. The original automated data system that was developed by the UOG Computer Center, called Informix Data System, crashed and a substantial amount of information was lost. The system was initiated in the Fall, 1990 and it crashed in the Spring, 1995. The PEDS staff found that the system was very repetitive of demographic information which was tedious and unnecessary, it wasn't user friendly, and lacked a manual for first time users and trouble shooting. It was useful for some data but lacking in other areas. The output lacked a legend for explaining various codes. For audiometric data, the need for more parameters and fields are needed because of the larger age group that is seen by the Audiologist at PEDS. The PEDS Staff described the elements of a system that would be required. The need for a good data management system as well as maintenance of computer hardware is a critical need.

F. Communication-telephones are located only in the reception areas and confidential calls are made in public areas. Telephones are needed within offices. A fax machine is also needed to transmit documents across agencies.

G. Consumer and Service Provider Surveys-the need for a parent survey to determine parent satisfaction of PEDS service and to generate consumer reports for service providers was targeted as an essential needs.

H. Transition PEDS-Guma Nene-The timeframe from testing to eligibility is 45 days. Testing is essential before placement to Guam Nene. Testing backlog creates a bottleneck prior to placement and precious time is lost for this age group. Paperwork bogs down the number of children who can be seen. Everybody is doing their own clerical support, when somebody gets ill the cancellations and backlog of both children and reports is staggering.

I. No Shows the no show rates for screening and evaluation is further hampered by the fact that there is no TA to remind patients of appointments.

J. Parent Enticements-the need for a mechanism to get parents more involved with the birth to 3 year children is needed.

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K. Cultural Issues-the need for a translator for different languages within Micronesia is needed to improve communication and to get better show rates. There is a need for a roster of speakers of Tagolog and the Micronesian languages.

L. There is a need for Staff Development opportunities to stay up to date on new techniques with the birth to 3 year population. Conference attendance using both on site and telecommunications was discussed.

M. Interagency collaborations with other agencies to be able to attend workshops funded by other agencies that is pertinent to serving the birth to 3 year population.

3. **What is the status of the PEDS Physical Plant? What aspects of the physical plant should remain unchanged? What improvements need to be made?**

A. The "home like" atmosphere of the Dean's Circle house at UOG has contributed positively and significantly to providing services. Many families, especially newly arrived Micronesian families find the present facility warm, welcoming, and they are more comfortable in the home-type context of PEDS.

B. PEDS site has been in violation of Section 504 - bathrooms, observation rooms, and test rooms are not accessible to wheelchairs. GSAT will be doing a complete evaluation of this issue.

C. Physical Therapy space and specialized equipment is needed. There is no privacy for therapy sessions and there is a big issue of sanitation when public areas are used for therapy sessions.

D. The growing staff coupled with office, equipment and clinical space requires that expansion of the current physcial plant is a critical area of need.

4. **What are PEDS fiscal resources? How has PEDS managed these resources? What are areas of need?**

The absence of a Director has made the coordination of fiscal resources and provision of services, which Dr. Blaz currently responsible for, an area needing immediate attention. The Part H Coordinator has been providing assistance but the interagency contributions which require continious monitoring is being neglected. Dr. Allen Crocker's observation that PEDS is doing a wide range of activities in the face of limited resources would indicates that PEDS is managing its resources to fullest extent, however the potential for increased cross agency supports, both in kind contributions and budget allocations from Part H, local contributions and private donations are still untapped.

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5. **Has PEDS provided the service to the Birth to 3 year population that it was designed to serve? What are strengths and weaknesses that have been identified by both families and service providers?**

GMH Birth Records from October to July indicate the following averages:

Average number of births per month:

299 x 12 months = 3,588

Average number of births < 2500 grams per month:

19 x 12 months = 228

Average number of birth requiring Intermediate Care per month:

61 x 12 months = 732

Average number of births requiring NICU Care per month:

7 x 12 months = 84

Average number of birth resulting in death per month:

2 x 12 months = 24

Part H Annual Report for 1995-1996 reported that 192 infants were determined eligible for Early Intervention Services. Combined projections for Intermediate Care and NICU Care infants totals 960 potential infants requiring EIS services in any given year. Based on last years counts only 2% are being identified.

6. **Given the findings from above, what is the prioritized plan for improvement to implement needed changes for the PEDS unit?**

Immediate:

1. Hire a Director for PEDS

2. Development of a 5 year comprehensive plan for PEDS which incorporates the needs of Guam and demonstrates a phase by phase plan for expansion of services.

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# TRIP REPORT-NEC*TAS MEETING-WASHINGTON D.C.

Conference Theme: Realizing the Promises for Young Children with Special Needs and Their Families

Dates: November 6-8, 1996

Report on Sessions Attended:

Wednesday-November 6, 1996

Registration-All registrations materials for both Guam Representatives were available and meetings not listed in the program were coordinated prior to arrival to Washington

(1) **Part H Coordinators Meeting**-This meeting was primarily focused on

(a) Introductions of new Part H Coordinators-I was introduced as the Representative for Leilani Nishimura, Part H Coordinator for Guam

(b) Review of State rotation for Steering Committee-This is a national effort to rotate Part H Coordinators and Part H FICC representatives to serve on a four member steering committee for 2 years to organize a Task Force on Formation of a Part H Organization (see Attachment #1), A major issue currently facing Part H is the application and review process.

(c) Election for the Vacant Representation position on the FICC-Nominations were made by the Part H Coordinators and Dr. Jean Johnson, State Director for Hawaii was elected to the vacant position

(d) Presentation on the Migrant Headstart Programs-this presentation involved the problems and issues confronting Headstart Programs for migrant families. The most significant aspect from Guam is the development of a bilingual resource listing to assist families who speak languages other than English. Guam may want to look into the Migrant Headstart Resource Access Project to develop a similar effort for the Micronesians, i.e. Chuukese families ( see AED Brochures - from the Migrant Head Start Region XII Resource Access Project)

(e) NEC*TAS Update-NEC*TAS has been refunded for another 3 years to provide technical assistance to Part H programs. There are 2 new major goals: (1) to develop a national forum cooperative to review and focus on vital national topics, particularly as they relate to funding and dissemination of best practices, (2) to provide technical assistance to the Federal Interagency Coordinating Council. An announcement was made that a needs survey was sent out to Guam from

NEC*TAS last October to expand the topical list for these goals. Managed Care was the most mentioned main topic. Don Yates did the needs survey and summarized the results on issues surrounding managed care- 20 states composed the national sample on the survey and results are will be available through NEC*TAS.

(f) NEC*TAS web site is: http://www.nectas.unc.edu - information from all the conference proceedings will be available 6 to 8 weeks, i.e. approved minutes of the Part H Meeting. There are 4 meetings throughout the year for Part H Coordinators and a monthly Executive Committee meeting that is done through conference call.

(2) **Plenary Session-Pat Trohanis:** ***Reflections on the Early Childhood Provisions of IDEA: Ten Years of Progress and Future Directions***-This session was primarily a welcoming session and retrospective look at the progress that has taken place in early childhood provisions of IDEA. A panel composed of the following people made brief presentations: George Jesien, EEPCD-Wisconsin (Moderator), Cindy Oser, Part H -Ohio, Elisabth Schaefer, Section 619-Massachusetts, and Sharon Barnhill, FICC Parent, Illinois. I was most impressed with the parent representative. Her presentation underscored the continued need to support programs and work toward more family supports because of the challenges, primarily economic, that face many young families today.

(3) **Informal Social and Tabletop Displays**-Information was gathered and is available on the following:

a) The Regional Resource and Federal Centers Network Newsletter: LINKS-A special education published by the Federal Resource Center for Special Education-An article on "Technical Assistance and Dissemination Projects Should Tap Potential of Internet, World Wide Web" was of interest for Guam

b) University of Oregon-College of Education-First Steps Information Sheet-This is an early intervention program designed to divert antisocial kindergartners from maladjustment, school failure, dropout, teacher/peer rejections, etc. It is a collaborative home and school intervention program.

c) A Parent's Guide-Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities-Compiled by The National Information Center for Children and Youth with Disabilities-Has 3 parts: (1) Questions and answers about early intervention services for infants and toddlers who have a developmental delay or who are at risk of a developmental delay (ages birth to 2 years), (2) Questions and answers about Special Education Programs and Services for Preschoolers with Disabilities (ages 3 to 5 years) (3) Questions and answers about programs and services for rural, native American, adoptive/foster and military families and their young children. Also a section on information about IDEA, a

Parent's dictionary of terms used in SpEd, , References for families, and a Parent Record Keeping Worksheet.

d) National Information Center for Children and Youth with Disabilities-A Guide to Children's Literature and Disability: 1989-1994

e) The Supportive Parenting Project-brochures used in the Zero-to-Three Hawai'i Project -Hawai'i Department of Health

f) Brochures from the Preschool Assessment System for Arizona: The Arizona Self Study Project, The Arizona Village Project, The Arizona EC-SPEED Project, and the Arizona Romper Project

g) Brochure on Infusing Cultural Competence in Early Childhood Programs: Multicultural Early Childhood Team Training from the George Mason University, Center for Human disAbilities and the Parent Educational Advocacy Training Center in Fairfax, Virginia

h) Project STEPS-Human Development Institute UAP-University of Kentucky-This is a project that is designed to provide training and technical assistance in the development of transition systems for children with disabilities birth through 8 years. Also included is a Project STEPS Bibliography. They will be conducting their 5th Annual National Transition Forum June 23-24 in Lexington, Kentucky. Theme: Building Supports for Local Communities.

i) Human Development Institute-1995-1996 Early Childhood Initiatives of the Human Development Institute-This is a 5 page brochure on the HD institute at the University of Kentucky and their activities and services

j) Nevada Parent Training and Information Center-Brochures on Neveda's family focused-community based support services for families of children with disabilities.

k) Introduction to the SPARK Creative Arts Curriculum-This is a literacy-based, culturally sensitive classroom curriculum that provides opportunities for preschool children to achieve developmental and school readiness skills by actively attending to stories and by participating in activities based on arts: music, art, and drama.

l) The National Information Center for Children and Youth with Disabilities: News Digest. Theme: You Are Not Alone: For Parents When They Learn That Their Child Has A Disability

m) American College of Emergency Physicians Emergency Data Set for Children with Special Needs-a data set to provide any health care provider with a directed summary of child's medical history, physical findings, and important unique management requirements. Includes examples of the ChUMS Project from the Ohio Department of Health and how they used the EMS-C Demonstration Grant to develop this data set and the EMS Project in New Hampshire called SKIP (Special Kids Information Program).

n) AGH Associates, Inc. Including All Children...in Childcare settings: A Training Package for early childhood settings, includes an Administrator's Handbook, ten self-paced modules covering CDA training, and a trainer's guide. Also has videos for awareness and caregivers.

o) Ages and Stages Questionnaires (ASQ): A Parent-Completed Child Monitoring System- the system is flexible, easy, low-cost means of monitoring the development of large numbers of infants and young children by using parents as first level screeners.

p) The Portage Project brochures-a program with a variety of training material for birth to 5 years. Includes a variety of areas. They provide a resource publication for early interventionists, a catalog of their programs, and a web site and email address for communicating issues and questions.

q) Zero to Three materials from the National Center for Infants, Toddlers, and Families. These materials include a a 1996 Publications catalog, opportunity to obtain the bi-monthly bulletin published by the center and information on the Zero to Three text entitled: New Visions for the Developmental Assessment of Infants and Young Children.

r) Child Development Resources material: includes the Early Intervention Early Childhood Special Program Series, Workshop offerings, video and print material, Trans/Team Outreach Abstract, SpecialCare Outreach for Children with Disabilities, Request for Training and Technical Assistance, Caring for Infants and Toddlers with Disabilities: New Roles for Physicians Outreach Project, SpecialCare Curriculum and Trainer's Manual, Parents and Caregivers in Partnerships, and Child Development Resources.

s) Project EXCEPTIONAL: A Guide for Training and Recruiting Child Care Providers to Serve Young Children with Disabilities, Vol. 1 & 2 - brochures on the scope of this training program from California

t) The Vermont material for their Family, Infant, and Toddler Project - this collection includes the material used in their programs used to inform families about different aspects of their program.

u) The Federal Resource Center for Special Education PLACEMAT-on this placemat is the names, addresses, phone, fax, email, and web address for all the Special Education Technical Assistance and Dissemination Network

Thursday-November 7, 1996

(4) **Plenary Session-*Updates for OSEP*-Tom Hehir, Director**-This session was a panel presentation that included Scott Brown, Associate Director of Early Childhood Team, Elizabeth Doggett, Special Assistant to the Director, and Ruth Ryder, Director of Division of Monitoring and State Improvement. The panel primarily covered the current activities in OSEP which affect the birth to 5 population. Many of the same topics covered in the Part H Coordinator's meeting were included.

(5) **FICC Meeting**-I sat in on this meeting to see what type of issues were going to be included. Dr. W. June Holstrum represented the CDC in Atlanta and Dr. Jean Johnson, the newly elected representative attended. It was good to see 2 of our Guam pioneers sitting on this council. There was no agenda passed out to non FICC members. I would like to see Guam become a representative at the council.

(6) **Part H Longitudinal Study: Characteristics, Services and Outcomes for Infants, Toddlers, and Their Families**-This session was packed but I included here as the presenter Kathleen Hebbeler from California has initiated a longitudinal study which follows a nationally representative sample of families and children in early intervention. It included the background, design, data collection procedures and schedules for the study. I will be obtaining the material from Kathleen by mail and maintain the documents of this study with the Part H evaluation process.

(7) **A Reception to Celebrate the 10th Year Anniversary and Contributions of the Early Childhood Provisions of IDEA-Co-Hosted by Pat Trohanis, NEC*TAS and Judy Heumann, OSERS**-This was the highlight of the NEC*TAS meeting, in my view. At this reception videos were shown when Judy Heumann and Pat Trohanis gave their statements to Congress in support of 99-457 and then had "family" testimonies about their experiences with their children over the 10 year period and how the children are doing now. It was very moving for many to see children with disabilities give their own verbal presentation on the differences that early intervention has made for them in their own adjustment. It was a tear jerking experience to hear what parents and siblings had to share on how they coped and were supported by the services provided through early intervention.

Friday-November 8, 1996

(8) **WRRC Breakfast at Washington Court-Shirley Coale**-WRRC invited Guam to this breakfast meeting and all the Micronesian representatives were present. The meeting was primarily designed to introduce everyone to the WRRC

staff and to encourage everyone to submit their requests for technical assistance.

(9) **Pacific Jurisdictions Session - Dottie Kelly & Pat Trohanis**-This meeting was designed to bring the Pacific jurisdictions representatives together to give each jurisdiction their summary of the TA activities provided by NEC*TAS. (Attachment for Guam included). Guam's activities are covered from October, 1994-August, 1996.

(10) **State Evaluations of Part H: System, Community, and Family/child Concerns**-This was the main reason I attended this conference. The session was conducted by Merle McPherson from Maryland, Richard Robets, Utah, Mark Innocenti, Utah, Linda Goetze, Utah, and other Part H Evaluators. Generally the session talked about how a group of Part H Evaluator has met a couple of times over the last few months. These are 10 states working with a group in Utah and they are developing an "Evaluation Consortium" - The national evaluation of Part H programs is very distinct from this consortium effort. Bonnie Strickland, MCH-FICC Subcommittee talked about continuity of services and the vision of a whole integrated system of services. By looking at Part H Programs: (1) What can be understood about the broad comprehensive services? There is a need to evaluate barriers from community perspective-look at multiple barriers- State and Federal issues, (2) What issues can we look at and learn from at the health aspect? (3) How do we develop a strategy to look at common questions among services providers, i.e. SSI-welfare reform. There was a discussion of what states are doing by discussing issues surrounding these questions. Different states are doing different plans of evaluation-each approaching the evaluation process based on their unique and different priorities. What are State bureacracy concerned about? What are their priorities? They proposed this possible model:

Systems Change ⟶ Specific Services

Questions of evaluation will drive the evaluation

Is Part H a systems change effort? For example, eligibility--Is this child eligible for services we provide? How many in the program are eligible under which category? How many eligible are receiving services for specific category of children? Are we reaching children who we are designed to serve? Are services available for population identified?

Areas across the continuum include:

eligibility
costs
funding
services
coordinator
outcomes
measures

Evaluation question will change depending on where your sta[illegible] on the continuum. The group will be preparing a paper for dissemination to ICC Chairs and Part H Coordinators. Should evaluation follow federal guidelines? Is measuring child outcomes very difficult? expensive? Does the evaluation of the child outcomes cost as much as the intervention? Reference to the longitudinal study - birth to 5 years was made. How much is being spent per child and what are we getting? Should outcomes drive the dollars? Yet, how can we know what are valued outcomes? What happens when a valued outcome is not within Part H purview? Is early childhood an organized system within your State?

Developmental gains
Family Well Being → Are these our valued outcomes?

**Outcomes** ↔ **Strategies with finite resources**
**Goals**
**Indicators**
↓
How are these different?

Are children prepared for Kindergarten?
Are Families well adjusted?
Are children fully included?

Then, there is the issues of self-sufficiency type of outcomes, i.e. is there welfare avoidance? Is there a return to the workforce? WHAT ARE WE MOST INTERESTED IN FINDING OUT? What about cost shifting, i.e. family costs such as family paying for transportation in home based vs. center based therapy? What about natural supports? i.e. physical therapy costs versus YMCA Service Teams?

What can Part H do to assist in developing a natural supports approach? Real systems change require a major financial investment and not necessarily to service coordinators to implement change. FICC Subcommittee is gathering themes from State Evaluations for meaningful understanding of Part H effectiveness.

A REPORT FROM WILL COME OUT WHICH FURTHER DESCRIBES THIS MODEL WHICH THE CONSORTIUM IS PUTTING TOGETHER. PART H COORDINATORS CAN REQUEST A COPY.

Overall Impressions: Many States are moving ahead with model programs, best practice dissemination, and resource and material development. Part H Coordinators are supporting these processes as they emerge within their States. Guam needs to become more involved and take the lead for the Micronesian area in terms of these efforts. The Part H meeting was an opportunity to see what other States are doing and it is my overall impression that Guam is behind in many of the prevailing issues facing early intervention services which makes the Part H sessions overwhelming, particularly when States present their updates on resources and services.

Thank you for the opportunity to attend the Part H meeting. Despite the jet lag from flying directly from Guam to Washington D.C., the meeting gave me an opportunity to see how Part H evaluations, in particular, are coming together.

Velma A. Sablan

PRESENTATION TO THE
GUAM INTER~~AGENCY COO~~RDINATING COUNCIL
December 12, 1996
Hyatt Regency Hotel
Velma A. Sablan, Research & Dissemination Core Faculty &
Pediatric Evaluation & Developmental Services Project Evaluator
Guam University Affiliated Programs

Presented to GICC

## CONTENT

- TRIP REPORT: National Technical Assistance Meeting for State and Jurisdictional Programs for Infants and Toddlers with Disabilities (Part H) and Preschool Grant Programs (Section 619 of Part H) and Early Education Program for Children with Disabilities (EEPCD) Projects of the Individuals with Disabilities Education Act (IDEA) - November 6 - 8, 1996 at Hyatt Regency, Washington D.C. on Capitol Hill

- STATUS REPORT ON THE PEDS EVALUATION: Technical Report update on the Self Study Evaluation of the Guam PEDS Unit

- GUAM PART H EVALUATION: PRELIMINARY PLANNING-Issues needing consideration based on the NEC*TAS Meeting on State Evaluations of Part H: System, Community and Family/Child Concerns and the Final Version of the Part H Self Study Instrument-Office of Special Education Programs, U.S. Department of Education

Oral Presentation

# The Self Study Evaluation of the Guam Pediatric Evaluation and Developmental Services (PEDS) Unit

# FINAL TECHNICAL REPORT

*(Micronesian palm frond baby carrier)*

**Submitted by:**

Velma A. Sablan, Ph.D.
Self Study Team Manager
Contracted Under Guam University Affiliated Programs
May 8, 1997
[Updated Sept. 8, 1997]